National Library of Canada
Bibliothèque nationale du Canada

Canadian Theses Service
Service des thèses canadiennes

Ottawa, Canada
K1A 0N4

NOTICE

The quality of this microform is heavily dependent upon the quality of the original thesis submitted for microfilming. Every effort has been made to ensure the highest quality of reproduction possible.

If pages are missing, contact the university which granted the degree.

Some pages may have indistinct print especially if the original pages were typed with a poor typewriter ribbon or if the university sent us an inferior photocopy.

Reproduction in full or in part of this microform is governed by the Canadian Copyright Act, R.S.C. 1970, c. C-30, and subsequent amendments.

AVIS

La qualité de cette microforme dépend grandement de la qualité de la thèse soumise au microfilmage. Nous avons tout fait pour assurer une qualité supérieure de reproduction.

S'il manque des pages, veuillez communiquer avec l'université qui a conféré le grade.

La qualité d'impression de certaines pages peut laisser à désirer, surtout si les pages originales ont été dactylographiées à l'aide d'un ruban usé ou si l'université nous a fait parvenir une photocopie de qualité inférieure.

La reproduction, même partielle, de cette microforme est soumise à la Loi canadienne sur le droit d'auteur, SRC 1970, c. C-30, et ses amendements subséquents.

NL-339 (r. 88/04) c

Canada

UNIVERSITY OF ALBERTA

PSYCHOSOCIAL CORRELATES OF INTERSTITIAL CYSTITIS

by

MARILYN JOYCE MURRAY-HUNDLEBY

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR

THE DEGREE OF DOCTOR OF PHILOSOPHY

DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

EDMONTON, ALBERTA

SPRING, 1990

National Library of Canada
Bibliothèque nationale du Canada

Canadian Theses Service
Service des thèses canadiennes

Ottawa, Canada
K1A 0N4

NOTICE

The quality of this microform is heavily dependent upon the quality of the original thesis submitted for microfilming. Every effort has been made to ensure the highest quality of reproduction possible.

If pages are missing, contact the university which granted the degree.

Some pages may have indistinct print especially if the original pages were typed with a poor typewriter ribbon or if the university sent us an inferior photocopy.

Reproduction in full or in part of this microform is governed by the Canadian Copyright Act, R.S.C. 1970, c. C-30, and subsequent amendments.

AVIS

La qualité de cette microforme dépend grandement de la qualité de la thèse soumise au microfilmage. Nous avons tout fait pour assurer une qualité supérieure de reproduction.

S'il manque des pages, veuillez communiquer avec l'université qui a conféré le grade.

La qualité d'impression de certaines pages peut laisser à désirer, surtout si les pages originales ont été dactylographiées à l'aide d'un ruban usé ou si l'université nous a fait parvenir une photocopie de qualité inférieure.

La reproduction, même partielle, de cette microforme est soumise à la Loi canadienne sur le droit d'auteur, SRC 1970, c. C-30, et ses amendements subséquents.

ISBN 0-315-60397-6

NL-339 (r. 88/04) c

Canada

UNIVERSITY OF ALBERTA

RELEASE FORM

NAME OF AUTHOR: MARILYN JOYCE MURRAY-HUNDLEBY

TITLE OF THESIS: PSYCHOSOCIAL CORRELATES OF INTERSTITIAL CYSTITIS

DEGREE: DOCTOR OF PHILOSOPHY

YEAR THIS DEGREE GRANTED: SPRING, 1990

PERMISSION IS HEREBY GRANTED TO THE UNIVERSITY OF ALBERTA LIBRARY TO REPRODUCE SINGLE COPIES OF THIS THESIS AND TO LEND OR SELL SUCH COPIES FOR PRIVATE, SCHOLARLY OR SCIENTIFIC PURPOSES ONLY.

THE AUTHOR RESERVES OTHER PUBLICATION RIGHTS, AND NEITHER THE THESIS NOR EXTENSIVE EXTRACTS FROM IT MAY BE PRINTED OR OTHERWISE REPRODUCED WITHOUT THE AUTHOR'S WRITTEN PERMISSION.

(SIGNED) Marilyn Murray-Hundleby

Suite 1603, 9929 Saskatchewan Drive

Edmonton, Alberta

T6E 5J9

Date: April 25, 1990

UNIVERSITY OF ALBERTA

FACULTY OF GRADUATE STUDIES AND RESEARCH

THE UNDERSIGNED CERTIFY THAT THEY HAVE READ, AND RECOMMEND TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH FOR ACCEPTANCE, A THESIS ENTITLED

PSYCHOSOCIAL CORRELATES OF INTERSTITIAL CYSTITIS

SUBMITTED BY MARILYN JOYCE MURRAY-HUNDLEBY IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY.

Dr. H. W. Zingle

Dr. J. D. Paterson

Dr. D. T. Shannon-Brady

Dr. W. H. Lakey

Dr. M. P. Browne

Dr. S. Robertson

Date: April 18, 1990

Dedication

To my parents, Irene and Kie.

To my family with love and affection, for their encouragement and support.

Abstract

Interstitial cystitis (IC), is a painful, chronic and often debilitating disease of the bladder. It is typically ten (10) times more common in women than in men, and often strikes women during their prime of life. Symptoms are a marked increase in urinary urgency and frequency, along with pain/and or burning.

While the etiology of interstitial cystitis is not fully known, recent medical researchers and physicians posit that lymphovascular, neurogenic, infectious, environmental, endocrinologic, psycho-neurotic, inflammatory (including autoimmune) mechanisms may be involved.

Psychological factors have been implicated as contributing to predisposition, onset, or the course of interstitial cystitis, however numerous studies noted in the urological literature have primarily addressed the physiological aspects of this condition. Psychological or psychosomatic components as they may relate to IC have only been given passing consideration.

In this exploratory study, psycho-social factors were investigated with fifty-six (56) IC patients, forty-four (44) urinary tract infection patients and forty-four (44) persons in a random control group. Four instruments were administered to all participants: the State-Trait Anxiety Inventory (Spielberger, 1983); the Adult Irrational Ideas Inventory (Davies & Zingle, 1970); the Internal-External Locus of Control (Rotter, 1966); the

Multidimensional Health Locus of Control (Wallston, Wallston & DeVellis, 1978) and the Millon Behavioral Health Inventory (Millon, Green & Meagher, 1982).

Thirty of the interstitial cystitis patients also participated in an indepth interview to gain insight into the experience of living with this disease.

The overall effect on all measures taken together was found to be significant. Differences among groups on individual variables were assessed using a univariate F test. While differences on eighteen (18) variables were not significant, the following individual sub-scales were found to be significant: **state anxiety, internal health locus of control, recent stress, premorbid pessimism, somatic anxiety, emotional vulnerability, gastrointestinal susceptibility, allergic inclination,** and **cardiovascular tendency.**

As a result of this exploratory investigation, further research is needed to examine in greater depth some of the significant findings, as well as to probe other variables which were not considered specifically within the confines of this study.

Acknowledgments

I would like to express my heartfelt thank you to the following people who have supported and encouraged the progress and completion of this project. Firstly, to a very special man, Dr. Harvey Zingle, my thesis supervisor, whose calm, gentle, caring and patient guidance made it all easier.

I feel most fortunate also for having a supervisory committee whose questions, ideas and direction were very helpful.

To Dr. John Paterson, thank you for your editorial suggestions and your wonderful gift of humor.

To Dr. Dustin Shannon-Brady, thank you for the invaluable critique of the organization of the Results chapter, as well as for your sharing and support.

To Dr. Patti Browne, for your positive manner in supporting students and for the pertinent discussions related to chronic illness and women's issues.

To a special physician, Dr. W. Lakey, for your interest in the project and your assistance in obtaining the patient populations in Alberta. Thank you.

To Dr. Sharon Robertson, for coming to Edmonton to serve as the external examiner, and for the valuable editorial comments which assisted in the final presentation of this document.

You have all taught me a great deal.

I would also like to thank Judy Hanatuke, for her gracious assistance in the initial phases of this study, particularly in organizing and contacting numerous patients.

To Dr. Ramon Perez-Marrero and Laurel Emerson for their

contribution in providing an interstitial cystitis patient population as well as for arranging to survey and interview participants.

To Phil McKenzie, for her talent in working with students through the process of the analyzing data. The time you so freely gave, and your friendship during this period of the study was significant.

To my family for their continuing love and support. To my parents Irene and Kie, who have always been there for their children.

To my sister Alison, my brother-in-law John, and nephew Scott. You gave me the boost when necessary! A special thank you to Alison for the hours of time involved in transcribing the tapes and in typing portions of the manuscript. I feel proud to have such a wonderful sister.

And lastly, to my friend and husband Glenn, who shows me daily that he loves and believes in me. You have helped me in so many ways.

TABLE OF CONTENTS

CHAPTER 1		Page
A.	INTRODUCTION	1
	Trait and State Anxiety	5
	Irrational Beliefs	6
	Locus of Control	7
	General Personality and Behavioral Traits	8
	Research Questions	10
	Operational Definitions	12
	Hypotheses	13
CHAPTER 2		
A.	REVIEW OF RELATED LITERATURE	14
	Interstitial cystitis	14
	Etiology of interstitial cystitis	17
	Historical Perspective of interstitial cystitis	17
	Statistics related to interstitial cystitis patients	22
	Personality and interstitial cystitis	24
B.	MIND BODY CONNECTION AND ILLNESS	30
	Studies linking thought and immune functioning	34
	Specific psychological attributes and illness	37
	Anxiety, stress, locus of control and illness	42
	Pessimism, learned helplessness and explanatory style	46

C. CONCLUDING COMMENTS 49

CHAPTER 3

A. METHODOLOGY 51

The Sample 52

Interstitial cystitis group 52

Urinary tract infection group 53

Random control Group 53

Adjusted sample 54

B. PROCEDURE 55

Pilot Study 59

C. INSTRUMENTS 62

State-Trait Anxiety Inventory 62

Adult Irrational Ideas Inventory 64

Internal-External Locus of Control 65

Multidimensional Health Locus of Control 67

Millon Behavioral Health Inventory 68

D. DELIMITATIONS AND LIMITATIONS OF THE STUDY 72

Delimitations 72

Limitations 73

E. DATA ANALYSIS 76

Statistical analysis 76

Analysis of Covariance 78

F. ANCILLARY INFORMATION 79

ICA Questionnaire 79

Interview Data 80

CHAPTER 4

A. RESULTS 82

Analysis of Research variables 83

Multivariate analysis of covariance 84

Comparison of Z-scores 84

Univariate F-tests and Post-Hoc Scheffe comparisons 88

B. Hypothesis 1 90

Results 90

Conclusion 91

C. Hypothesis 2 91

Results 91

Conclusion 91

D. Hypothesis 3 92

Results 92

Conclusion 93

E. Hypothesis 4 93

Results 93

Conclusion 100

F. Interstitial Cystitis Association Questionnaires and Interviews 104

Subjective inconvenience to daily living 104

Words used to describe illness 105

Pain and interstitial cystitis 106

Depression 107

Body Tension 108

Unexpressed anger 108

Perfectionism 109

Urological problems during childhood 110

Sexual functioning 111

Traumatic events in childhood 111

CHAPTER 5

A. DISCUSSION 115

State-Trait Anxiety 116

Irrational Ideas 117

Locus of Control 117

Multidimensional Health Locus of Control 118

Internal health locus of control 119

Powerful Other health locus of control 120

Chance health locus of control 121

Millon Behavioral Health Inventory 122

Coping styles 122

Psychogenic attitude scales 123

Psychosomatic correlate scales 129

Prognostic indices 132

B. CONCLUDING COMMENTS 136

C. IMPLICATIONS 138

REFERENCES 142

APPENDIX A 159

APPENDIX B 187

APPENDIX C 200

APPENDIX D 203

APPENDIX E 205

List of Tables

Table		Page
1.	Linear relationship between dependent variables and age	78
2.	Testing for Homogeneity of regression hyperplanes	78
3.	Multivariate test of Covariance	84
4.	Adjusted Z-scores on all variables for the IC, Urinary Tract Infection and Random Control Groups	85
5.	Univariate F-tests among groups on all variables	89
6.	Scheffe comparisons on State Anxiety for the IC, Urinary Tract Infection, and Random Control Groups	90
7.	Scheffe comparisons on Internal Health Locus of Control	93
8.	Scheffe comparisons on Recent Stress	95
9.	Scheffe comparisons on Premorbid Pessimism	96
10.	Scheffe comparisons on Somatic Anxiety	97
11.	Scheffe comparisons on Gastrointestinal Susceptibility	98
12.	Scheffe comparisons on Allergic Inclination	98
13.	Scheffe comparisons on Cardiovascular Tendency	99

14. Sceffe comparisons on Emotional Vulnerability 100

List of Figures

Figure		Page
1.	Disease susceptibility model	29
2.	Comparison of Z-scores for the IC and Random Control Groups	86
3.	Comparison of Z-scores for the IC and Urinary Tract Infection Groups	87

List of Appendices

Appendix		Page
A.	Questionnaires and Demographic Data	159
B.	Interstitial Cystitis Association Questionnaire	187
C.	Letter to Urologists in Alberta	200
D.	Letter to Random Sample	203
E.	Structured Interview Schedule	205

CHAPTER 1

Introduction

Through the ages, healers and shamans alike, have referred to the remarkable and enduring effects that words, attitudes and beliefs have on the physical body. Epictetus (60 A.D.) noted that individuals could exude considerable control over their physiological reactions, and the degree of upset experienced, depending upon how they viewed a particular life situation or event.

A multitude of these simple truths still hold considerable wisdom today. This is particularly true in terms of how we are coming to conceptualize health and disease, as well as the types of individuals who may become ill. Hippocrates, the Father of Medicine, admonished students and colleagues alike to carefully consider the whole person (mind, body, spirit, and emotions) in order to properly scrutinize and accurately treat health concerns. In a similar vein, the famous British physician, Sir William Osler postulated that it was important to ask not what kind of illness the patient has, but rather what kind of patient has the illness.

These early notions correspond to our modern day view of the unity of body and mind, stressing that health occurs, when there is homeostasis or natural harmony in the body, and disease when there is imbalance or disharmony (Borysenko, 1987; Bry & Blair, 1978; Justice, 1988; Ornstein & Sobel, 1987).

For many medical practitioners, the suggestion that emotions, attitudes and beliefs directly influence bodily processes, still remains within the realm of folklore. However, rather fundamental and remarkable breakthroughs are emerging in the fields of psychosomatic medicine, the neurobiology of emotion, psychoneuro-immunology, and neuroimmunomodulation which continue to shed light on the phenomenal mechanisms of the mind-body connection (Ader, 1981; Ader & Cohen, 1982; Borysenko, 1987; Pert, 1986a, 1986b; Pert, Ruff, Weber & Heikenham, 1985). The initial efforts of such prominent researchers as Alexander (1950), Beecher (1955, 1956), Cannon (1939, 1945), Dunbar (1943, 1947, 1954), Menninger (1938, 1946) and Selye (1956) paved the way for extensive research which continues today.

Most recently, the healing system and the belief system have been recognized and elevated in their importance in linking mind and body (Achterberg, 1985; Pearsall, 1987). They are seen to be in continual communication with the other major regulatory systems of the body, indicating the intricate interplay of thoughts and emotions on physiology (Brown, 1984; Cousins, 1989; Siegel, 1986, 1989).

Achterberg (1985), Dorian and Garfinkel (1987), LeShan (1977) and Rogers, Dubey & Reich (1979) have gathered empirical evidence which demonstrates the importance of the mind and beliefs in activating the healing system. Ader (1983, 1985), Ghanta, Hiramoto, Solvason and Spector (1985), Locke and Colligan (1986) and Solomon

(1985) considered by many to represent the new psycho-neuroimmunologists, have similarly contributed extensive data further solidifying this link.

Many prominent researchers point out that the disease process is complex, in that it results from many factors which magnify and increase over extended periods of time. Biological considerations combined with behavior, emotions, continued activation of the fight-or-flight response, attitudes, beliefs, satisfying relationships, and the sense of internal control we assume in our life all play significant roles in disease susceptibility (Benson, 1975, 1984; Cousins, 1979, 1983, 1989; Hall, 1982, 1983; O'Regan, 1988; Pearsall, 1987; Pert, 1986a, 1986b).

Hans Selye's life work contributed significantly to the mind-body connection, when he acquainted the world with the concept that psychological stress can be a factor in disease. He pointed to the clear distinction that it is not what stresses us that is of importance, but rather our reactions and response to the demands of stress. This inter-actional perspective has been well supported by current researchers (Antonovsky, 1979, 1987; Brown, 1984; Cox, 1978; Everly & Rosenfeld, 1981; Hiebert, 1983, 1985, 1987; Kasl, 1984; Kobassa, Maddi & Courington, 1981; Magnusson, 1982).

Our perceptions of a stressful situation, excessive anxious thought, along with the beliefs and attitudes we hold in terms of a problem or challenge in our life, influence the chemical messages transmitted from our brain to our body (Justice, 1988; Pearsall,

1987; Pert, 1986a, 1986b; Pert, Ruff, Weber, & Heikenham, 1985).

Individuals also react to imagined or anticipated fears, such that certain physiological changes including arousal, muscular tension, initiation of the "fight or flight" response, and preparedness for action, also result.

"Dysponesis" was a term coined by Dr. George Whatmore, to describe the repeated bracing or tensing of muscles in response to small annoyances or hassles in daily living. Pearsall (1987) and Stroebel (1982) suggest that it is this chronic dysponesis, which may eventually result in illness or disease, due to continual wear and tear on body organs.

Contemporary researchers continue to detail the importance of the 'human factor' in prevention as well as causation of disease (Dossey, 1982). Anxiety, helplessness-hopelessness, depression, anger, pessimism, stress, habitual reactions to stressful events, sense of control and hostility are all multifarious personality traits which constitute the 'human factor' in health or disease (Antonovsky, 1984; Engel, 1971; Eysenck, 1987; Jemmott & Locke, 1984; Kobasa, 1979). The researcher addressed some of these factors and other themes with respect to a chronic, and sometimes degenerative urological condition known as interstitial cystitis.

Researchers investigating the etiology of numerous illnesses have focused on how anxiety, the perception of stress or a stressor and limited coping resources, interact with biological determinants to launch a disease process. Meares (1987) and Schwartz (1987)

questioned whether anxiety and stress contribute in some way to the onset of interstitial cystitis, or whether they are the result of the chronic nature of the syndrome.

At this juncture, no empirical studies appear to have examined the intricacies of such links. This research, investigated more fully the inter-relationship between interstitial cystitis, anxiety, irrational beliefs, locus of control, generalized personality traits or coping behavior and psychogenic attitudes and stress.

Trait and State Anxiety

Trait anxiety (T-Anxiety) is conceptualized as relatively stable individual differences in proneness to anxiety. State anxiety (S-Anxiety), on the other hand, refers to transitory emotional states or conditions which are characterized by subjective, consciously perceived feelings of tension, along with heightened autonomic nervous system activity (Spielberger, 1966). Operational definitions of Trait anxiety point to the differences between subjects in the tendency to respond to situations with elevations in State intensity.

As a psychological concept, trait anxiety has the characteristic of what Campbell (1963) called "acquired behavioral dispositions". Such residues of past experience predispose an individual both to view the world in a particular way and to manifest object consistent response tendencies (Campbell, 1963).

Previous studies have confirmed that anxiety can often be a factor in interstitial cystitis (IC). However, as a number of researchers have emphasized, it may be as a result more than a cause of interstitial cystitis (Meares, 1987; Schwartz, 1987). Unfortunately, the type of anxiety identified has not been clearly defined. The researcher specifically examined the relationship between IC and trait anxiety (T-Anxiety) as well as state (S-Anxiety) to determine more explicitly if a certain type of anxiety is related to interstitial cystitis.

Irrational Beliefs

Many researchers have shown that developing a positive, rational attitude, a strong sense of control, and peace of mind engenders good health (Bandura, 1985; Benson, 1984; Good, 1981; Green & Green, 1975; Hamburg, Elliott & Parron, 1982; Justice, 1988; Langer, 1983; Maddi & Kobasa, 1984; Nathan, 1985; Rodin, 1979).

Albert Ellis, maintains that individuals who operate from an irrational perspective tend to create and experience greater feelings of stress and anxiety when compared to their more rational counterparts.

In essence, Ellis in his ABC theory of Rational Emotive Therapy (Ellis, 1962, 1984) postulated that when some fact or event (A) occurs, it is one's evaluative thoughts or beliefs (B), about the (A) which determine the emotional and behavioral consequences (C). The key ingredient of course is (B), the evaluative thoughts communicated through internal self-talk.

This internal communication formulated from one's early life experiences, is typically punctuated with shoulds, oughts, and musts, along with perpetual self-downing. Anxiety, and detrimental stress result when self talk is founded upon irrational, illogical and untrue beliefs. It is the distortion of thought that results in irrational reactions and behaviors deleterious to a healthful, stress-free, happy life.

In light of Ellis' theory, it was thought beneficial to consider whether interstitial cystitis patients evidence high levels of irrational thinking, such that they also experience elevated levels of anxiety and stress. Such a measure would not elicit transient irrational thinking, because Ellis' paradigm is based upon the measurement of a belief system that has developed over the course of one's life.

Locus of Control

The concept of locus of control was introduced by Rotter (1966) to represent the amount of control individuals believe they have over what happens in their lives. Individuals who believe that events and situations occur as a consequence of their own behavior, actions or personality, are said to exhibit an internal locus of control, while individuals who feel that the events in their lives occur as a result of fate, luck, chance, or the efforts of powerful others are said to have an external locus of control.

A strong belief in one's inner strengths and abilities, or having an internal locus of control, appears to foster improvement, remission or even elimination of many symptoms of a disease condition (Benson, 1984; Justice, 1988; Kamen & Seligman, 1987; Peterson & Seligman, 1987; Peterson, Seligman & Vaillant, 1988).

It could be that individuals who do not experience relief or realize some sense of mastery over a physical condition may have an external locus of control. This may be due to the belief that the medical profession is the only viable means of achieving a cure or salutary effect, and that the individual has little impact on the outcome.

Interstitial cystitis patients tend to frequent urologist's offices, due to the chronicity and painful nature of the condition. It may be that individuals experiencing this enigmatic syndrome, rely solely upon their physician to prescribe medications or perform procedures to elicit some relief. A sense of having little control over one's general life situation, along with the belief that it is the physician alone who can elicit relief for the patient, may increase the stress and anxiety already experienced by the majority of women presenting with this physical complaint.

General Personality and Behavioral Traits

Many illnesses including cancer, rheumatoid arthritis, peptic and gastric ulcers, migraine headache, cardiac disease, and ulcerative colitis to name a few, have been linked in part to

stress, anxiety, depression, locus of control, hopelessness and/or some other personality factor. On the other hand, a computer search of empirical investigations directly examining interstitial cystitis and personality traits, attitudes, psychosocial or psychosomatic factors was indeed limited.

Interstitial cystitis is only one of a multitude of disease conditions which could be explored in terms of psychosocial factors. Many writers, in summarizing the research literature on interstitial cystitis, have made reference to some emotional or psychosomatic concomitant of the condition. Yet, no clear evidence of the impact of such factors exists.

Just the frustration experienced by both patients and physicians alike, in dealing with the symptoms and attempting to alleviate the debilitating pain, points to the need for further research (McCormick & Vinson, 1989). The complex nature, and the apparent multiplicity of potential factors already alluded to in connection with this condition, would imply the need for a more eclectic or holistic paradigm to investigate and treat this difficult syndrome.

A study specifically designed to examine the presence of a link between anxiety, irrational beliefs, external locus of control, behavioral health attitudes, and personality or coping traits may in some way prove helpful in responding to this condition with further insight. Personal coping style, indications of daily stress levels and emotional well-being, could assist in tailoring treatment programs to the needs of IC patients.

At this time the typical means of treating interstitial cystitis is through medication or a variety of surgical procedures. Within this study the researcher examined several possible psychosomatic mechanisms which may contribute to onset, and then possibly over time contribute to the chronicity of this often unrelenting condition.

Research Questions

Several pertinent questions were presented for investigation. The first question sought to determine whether there was a relationship between women diagnosed with interstitial cystitis and measures of state and trait anxiety. An inherent supposition was that women diagnosed with interstitial cystitis would evidence higher levels of trait anxiety which in turn would predispose them to increased state anxiety.

A second question asked whether there was a relationship between irrational thinking and interstitial cystitis. An abundance of irrational, and illogical thoughts which are seen to create considerable anxiety and distress could in some way be associated with the initiation or aggravation of this urological condition.

A third question addressed whether there was a relationship between locus of control and women diagnosed as having interstitial cystitis. The internality-externality construct was generally investigated, and then more specifically as it pertained to health. Women having high scores indicating a greater degree of external

locus of control may believe that they have limited control over what happens to them in life as well as in the management of their health care.

Another question was whether women diagnosed with interstitial cystitis have a certain coping style which may play a role in this disease process as well as in exacerbating symptoms. More effective management strategies and better patient health-care may be assisted through increased understanding of the general personality characteristics revealing personal functioning.

A final question was whether there was a relationship between patients diagnosed with interstitial cystitis and certain themes they share from their growing up years as well as how they experience life presently. A structured interview was utilized to capture insights possibly not available through standard inventories or questionnaires.

At this time, there is a conspicuous lack of research which addresses whether personality factors, attitudes and coping style influence urological dysfunction as expressed through the condition, called interstitial cystitis. In this study a number of psycho-social variables were examined to determine whether they relate to, or in some way may effect the course of this painful bladder disease.

Operational Definitions

Anxiety will be defined as scores obtained on the State-Trait Anxiety Inventory (STAI Form Y, Spielberger, 1983).

Irrational Thinking will be defined as scores obtained on the Adult Irrational Ideas Inventory (AII, Davies & Zingle, 1970).

External Locus of Control will be defined as scores obtained on the Internal-External Locus of Control (I-E Scale, Rotter, 1966) and the Multidimensional Health Locus of Control Scale (MHLC, Wallston, Wallston & DeVellis, 1978).

Behavioral Health Attitudes and Coping Styles will be defined as scores obtained on the twenty (20) sub-scales of the Millon Behavioral Health Inventory (MBHI, Millon, Green & Meagher, 1982).

HYPOTHESES

Hypothesis 1

Female interstitial cystitis patients will score higher on a measure of anxiety than will persons in a female urinary tract infection group or a random control group.

Hypothesis 2

Female interstitial cystitis patients will score higher on a measure of irrational thinking than will persons in a female urinary tract infection group or a random control group.

Hypothesis 3

Female interstitial cystitis patients will score higher on measures of external locus of control than will persons in a female urinary tract infection group or a random control group.

Hypothesis 4

Female interstitial cystitis patients will score differently on measures of behavioral health attitudes and coping styles (as stated below in the twenty (20) sub-hypotheses), than will persons in a urinary tract infection and a random control group.

a. Introversive Coping Style
b. Inhibited Coping Style
c. Cooperative Coping Style
d. Sociable Coping Style
e. Confident Coping Style
f. Forceful Coping Style
g. Respectful Coping Style
h. Sensitive Coping Style
i. Chronic Tension
j. Recent Stress
k. Premorbid Pessimism
l. Future Despair
m. Social Alienation
n. Somatic Anxiety
o. Gastrointestinal Susceptibility
p. Allergic Inclination
q. Cardiovascular Tendency
r. Emotional Vulnerability
s. Life Threat Reactivity
t. Pain Treatment Responsivity

CHAPTER 2

Related Literature and Research

This chapter begins by looking at the literature related to a chronic urological condition, known as interstitial cystitis. Following this, an overview of research supporting the mind-body connection in illness is presented. The relationship between disease and specific psychological attributes such as anxiety, stress, irrational thinking, locus of control and health-related personality traits or pre-disposition is similarly explored.

Interstitial Cystitis

Interstitial cystitis, (IC), is a chronic disease of the bladder marked by severe pain, urgency and frequency. Held, Hanno, Wein and Pauly, (1987) quote a statistic of 20,000 to 90,000 present cases of interstitial cystitis in the United States. The upper estimate of cases yet to be diagnosed, is believed to be at least 5 times this figure (Hanno, 1989).

First detailed by a French physician in 1836, interstitial cystitis was again described and established in 1914, by Guy Hunner, a U.S. gynecologist. Hunner noted the presence of congested blood vessels on the back wall of the bladder which tended to disperse into twig like branches. This state was so named *Hunner's ulcer*.

Gillespie (1986) and Sant (1989) suggest this may be somewhat of a misnomer with respect to diagnosing IC today, due to the fact that Hunner's patients exhibited advanced stages of the disease, where "classic" ulcers are more commonly found. This specification for determining interstitial cystitis, is believed to result in numerous cases going undiagnosed, due to the absence of *Hunner's ulcer* (Sant, 1989).

The rather diverse symptoms, along with endoscopic and histologic findings through biopsy and differences in how patients respond to prescribed treatments has prompted the view that there may be an early, or non-ulcer form, as well as the more classic and ulcerative type of interstitial cystitis (Enerback, Fall & Aldenborg, 1989; Sant, 1989).

Generally, inflammation exists in the interstitium or space between the bladder lining and the bladder muscle. While no bacteria are typically present, interstitial cystitis often mimics the symptoms of a bladder infection.

Messing (1986) describes the syndrome as having irritative voiding characteristics, sterile, cytologically negative urine, and corresponding cystoscopic findings. To establish a diagnosis cystoscopy examination is essential, so as to document bladder capacity, bleeding sites, hemorrhages, streak ulcerations of the tissue, and the presence of corkscrewlike capillaries. These guideposts for determining the presence of IC are much more encompassing than the singular "ulcer" suggested by Hunner almost 75 years ago.

Initially, it may appear in a rather mild form as the need to void frequently. However onset may be extremely acute, in which case the patient generally recalls the exact day it began (Hanno, 1989, p. 150). Discomfort is experienced as the bladder's protective inner lining becomes inactivated. At a more advanced state, the bladder becomes ulcerated and scar tissue forms, causing shrinkage and thereby diminishing the bladder's storage ability. This situation can result in the uncomfortable feeling of needing to empty the bladder continually. Often there is little or nothing to void, and the individual is left with discomfort or extreme pain.

The extent of this pain has been likened to placing a burning charcoal briquette, or Absorbine Junior liniment into the bladder, or zapping it with many little electric shocks. Ratner (1987) a medical practitioner and interstitial cystitis patient herself, suggests that at present, a patient's best scenario is to learn to live with the distress, and in extreme cases to possibly live without a bladder.

Typically, interstitial cystitis is 10 times more common in women than men (Hanno, 1989). While it generally appears during middle age (Messing & Stamey, 1978; Oravisto, 1975), more women in their 20's 30's and 40's are being diagnosed (Hanno, 1989). Interstitial cystitis has also been diagnosed in children (Chenowith & Claywater, 1960; Geist & Antolak, 1970; McDonald, Upchurch, & Sturdivant, 1953) and the aging population (Guerier, Roberts, & Slade, 1965; Messing & Stamey, 1978; Oravisto, 1975).

Etiology of Interstitial Cystitis

The etiology of interstitial cystitis is not fully known. More recent medical researchers and physicians have suggested that lymphovascular, neurogenic, infectious, environmental endocrinologic, psycho-neurotic, inflammatory (including autoimmune) mechanisms may be involved (Edwards, Bucknall & Makin, 1986; Gil-Vernet, Gonzalez & Fernandez, 1960; Hand, 1949; Hanno & Wein, 1987; Lose, Frandsen, & Holm-Bentzen, 1987; Messing, 1986; Oravisto, 1980; Parsons, 1987; Weaver, Dougherty & Natoli, 1963).

The release of histamines from mast cells in IC patients continues to be investigated (Aldenborg, Fall, & Enerback, 1986; Feltis, Perez-Marrero, Emerson, 1987; Lynes, Flynn, Shortcliff, et. al.,1987). Mast cells, functioning in hypersensitivity reactions, have significant impact on the inflammatory process in smooth muscle as well as in certain organs (Galli, Dvorak, & Dvorak, 1984; Sant, 1989). Again, uncertainty persists in labeling IC as an autoimmune disease and further evaluation will be necessary (Anderson et al., 1989).

Well known researcher, Grannum Sant (1989) concludes that IC may not have a singular etiology. Rather, it may be a symptom complex of assorted causation which in the end produces the symptoms linked to interstitial cystitis.

Historical Perspective

Earlier investigations of perplexing urinary conditions provide

some historical perspective in this area. Aboulker and Chertok (1951) reported a urinary disorder that they termed "cystalgie a urines claires" (cystology of clear urine). Although the specifics of this condition were probed, no adequate rationale or explanation for the disease was found, even though attempts were made to explain away the peculiarities of the disorder. Dunbar (1954) noted that this condition occurred almost exclusively in women, stemming from nervous, infectious, allergic, and endocrine origins.

One of the earliest investigations of interstitial cystitis, involving twenty-five patients suffering from this complaint, led Aboulker and Chertok (1951) to the opinion that a particular mental attitude was characteristic. In many cases the appearance of the symptoms followed closely some traumatic experience in the patient's life, and quite as frequently disappearance of the symptoms and cure were effected by psychotherapy alone (Dunbar, 1954).

Montassut, Chertok and Aboulker (1951) point out the work of French physician Janet, who in 1890 observed an incurable false urinary affliction which he apparently treated with some success. An English translation of Janet's method of treatment indicated that the best way to improve the urinary psychopathological condition of the person, consisted of getting the patient to forget her/his pain as much as possible, and to distract the mind from her/his bladder. Janet apparently indicated that in each case, psychotherapy ameliorated or cured the ailment. This enigmatic urological entity described above, sounds very much like the syndrome known as interstitial cystitis.

Dunbar (1954) cites the work of Born as well as Mosso and Pellacini, who respectively suggest that the bladder is the most responsive of aesthesiometers, more sensitive than blood pressure. It was also their belief that the bladder was the "mirror of the soul" (p. 488). A unique organ, the bladder is hollow and vulnerable to the will. The bladder's reaction to psychological influences has been illustrated in experiments where the direction to urinate resulted in an increase in detrusor tonus. Initially the change is gradual and then it hastens until the tonus is equivalent to that of the sphincter.

Dunbar (1954) writes that voluntary control functions by arousing this tonus, and emotional or psychological factors (affects), operate similarly. Of interest is Dunbar's comment that the bladder is vulnerable to these influences through the nerve pathways as well as through blood distribution. Mosso and Pellacini (1925, p. 489) were of the opinion that everything influencing the blood pressure influences the bladder.

The bladder may be psychogenically influenced by excitement, fear or nervousness in given situations. Cannon (1929) refers to the involuntary voiding of the bladder during times of extreme mental stress, wherein veterans of wars testify that just before the beginning of a battle many of the men have to retire temporarily from the firing line (p. 31).

Schwarz (1925) as cited by Flanders Dunbar (1954) suggested that predispositions to disturbance of the bladder may be acquired as a

consequence of psychological influences. He later called attention to the need for a corroborating connection between psychological situations and organ symptoms. It is interesting to note that some sixty years later this has not been investigated at any length, yet the incidence of cases continues to rise. Dunbar (1954) noted a very meager urological literature, with respect to psychosomatic issues and urological conditions. Although a void in reported research was apparent, it was thought that many practicing physicians utilized some psychosomatic approach in their practice.

A computer search of studies linking interstitial cystitis with such terms as personality, psychosomatic, psychosocial, psychodynamic, personal attitudes, or self efficacy, revealed a paucity of information. Only one recent inquiry specifically examined psychological factors as they related to this bladder condition. Keltikangas-Jarvinen, Auvinen and Lehtonen (1988) found that female interstitial cystitis patients were more externally controlled, displayed greater psychological helplessness and exhibited inadequate coping skills in dealing with everyday stress. These factors were shown to not only be related to disease onset, but to be influential in coping with disease generally.

A number of researchers have suggested that a habitual state of tension or psychosomatic problems might produce sustained muscle spasms with ischemia and a chronic inflammatory process of the connective tissue of the bladder (Bowers, Schwarz & Leon, 1958; Hand, 1949; Straub, Ripley & Wolf, 1949).

Bowers, Schwarz, and Leon (1958) note that many practitioners believe interstitial cystitis exhibits the same relationship to diseases of the urinary bladder as ulcerative colitis does to the intestinal tract. Interstitial cystitis was also likened to peptic ulcers of the upper gastrointestinal tract. In each of these conditions, compelling psychosomatic underpinnings were strongly intimated.

A case report of a 29 year old female patient exhibiting chronically severe symptoms of interstitial cystitis, was discussed at length in an article by Bowers, Schwarz, and Leon (1958). Of particular interest was the transcript of conversations relating life experiences and feelings, which the authors believed contributed to the tragic physiological and psychological condition of the young woman. Ultimately, the woman's bladder was surgically removed. This radical treatment unfortunately did not correct the problem, as the same symptomatology persisted, to the extent that she questioned whether the procedure had in fact been done.

Some pertinent descriptors of the patient's personality and life pattern suggest that she could never cry or talk back, as she was told "that's for sissies." She reflected upon feelings of being punished, but when confronted with feelings of family members in this regard, she would deny any resentment or hostility. Other traits presented were: preferring to work alone, having few friends, and seldom engaging in social events or activities.

Bowers, Schwarz and Leon (1958) believe that in terms of this patient, the bladder served as a pathway for the discharge of unconscious hatreds, and beginning with an infection during puberty, a vicious cycle of hate, repression, enuresis, superimposed infection, inflammation, and iatrogenic traumas eventually led to the development of chronic interstitial cystitis (p. 301). The history of this patient, however, suggests that the bladder condition was only one aspect of an overall emotional problem of greater depth and breadth.

Bowers and Lattimer (1957), Hand (1949), and Hunner (1930) also noted an association between interstitial cystitis and emotional concerns, however no documentation of cases in terms of psychiatric conditions has ever been investigated to any extent.

The incidence of collagen disease and allergies has often been implicated with interstitial cystitis (Dees, 1953; Gil-Vernet, Gonzalez & Fernandez 1960; Hand, 1949). Selye (1946) likens collagen diseases to diseases of adaptation. Here the general adaptation syndrome is seen as the totality of all nonspecific systemic reactions of the body resulting from continued exposure to longstanding stress. It may be possible then, that the nonspecific characteristics of interstitial cystitis could be accounted for in part at least on the basis of an adaptation disease.

Statistics Related to IC Patients

An interesting and informative pilot study conducted jointly by the Interstitial Cystitis Association and the Urban Institute in

Washington D.C., produced some initial data relating characteristics of this perplexing condition and the psychosocial implications of the problem. The documentation obtained from this study profiles the typical IC patient as approximately 32 years of age, with an average of seven years between onset of symptoms and final diagnosis of interstitial cystitis.

Interstitial cystitis patients visited 2 to 5 physicians prior to receiving a diagnosis. The economic implications of this process are profound, with a quoted expenditure of 170 million dollars in an average year. This is 116.6 million dollars more than a comparable non IC population (Held, Hanno, Wein & Pauly, 1987; Slade, 1989).

Forty percent of the women were unable to work; 58 percent were unable to have intercourse and 28 percent had gone through a breakup of relationship with their spouse or companion (Held, Hanno, Wein & Pauly, 1987). McCormick and Vinson (1988) surveyed IC patients and found lowered sexual self esteem, an increased sense of anxiety when contemplating future sexual encounters, disrupted sexual arousal and difficult or painful intercourse.

Held, Hanno, Wein and Pauly (1987) report that in many cases, interstitial cystitis restricts one's life as well as reducing the quality of living to a level below that of white women experiencing end stage renal disease. Twenty-five (25) percent of IC patients indicated they felt no relief of symptoms from any treatment.

The sometimes desperate state of women experiencing this syndrome was reflected in the statistic that twelve (12) percent of

respondents had attempted suicide and more than fifty-five (55) percent had considered this drastic step at least once in the course of their illness (Ratner, 1987; p. 44).

Ratner (1987) is of the opinion that the aforementioned individuals represent a group of women who have given up consulting urologists. The joint frustration felt by both physician and patient in being told that there is little that can be done to alleviate the symptoms permanently, or that they should consult a psychiatrist to deal with stress of their neuroticism, has contributed to feelings of isolation for many IC patients.

Personality and Interstitial Cystitis

The recognized reference, Campbell's Urology (1979), describes interstitial cystitis as a disease "that is taunting in its evasion of being understood, and may represent the end stage of a bladder that has been made irritable by emotional disturbance" (p. 976).

The most recent edition of Campbell's Urology (1986) points out that for over fifty years, urologists have been impressed that certain personality traits are common to many patients with interstitial cystitis (Bowers, Schwartz & Leon, 1958; Hunner, 1930; Walsh, 1978; Worth & Turner-Warwick, 1973). There does not appear to have been however, any systematic study of this factor.

Larrian Gillespie (1986, p. 57) draws attention to the well known notion that chronic non-bacterial cystitis may be caused by emotional distress. Gillespie's (1986) first efforts in 1980 to

diagnose and treat IC patients, gave rise to the belief that these individuals were characteristic of the Type-A personality. While some patients reported having such tendencies, Gillespie is now of the opinion that such personality traits are irrelevant to the disease.

Meares (1987) notes that many clinicians hold the view that interstitial cystitis is a psychosomatic illness. The question of whether anxiety, stress, or depression cause, or are the effect of the disease, still clouds the whole issue of this enigmatic syndrome.

This view was also reflected in a recent review of the current literature of interstitial cystitis, which produced numerous articles reviewing etiology, treatment procedures and outcomes in the management of this disease. Only one study appears to have specifically addressed the issue of personality characteristics related to this perplexing problem (Keltikangas-Jarvinen, Auvinen & Lehtonen, 1988). This research culminated with the premise that "psychological factors are so evidently involved in interstitial cystitis that they have to be taken into consideration in treatment" (Keltikangas-Jarvinen, Auvinen & Lehtonen, 1988; p. 72).

Confounding influences such as severity of symptoms, length of time the symptoms have been endured before a correct diagnosis was made, the unpredictable response to any but the most drastic of treatments, along with the insinuations of frustrated physicians, makes the evaluation of underlying neuroses somewhat difficult from a methodological perspective.

Furthermore, there have been no reported successful therapeutic interventions attributed to psychotherapy, which have been confirmed by follow-up cystoscopic assessment. Certainly until such evidence is provided, the neurotic traits suggested can only be considered a response to the chronic nature of the condition, than to its cause (Messing, 1986).

A recently published Finnish study examined psychological and personality factors in 31 female interstitial cystitis patients and 24 women experiencing acute bacterial cystitis. Keltikangas-Jarvinen, Auvinen and Lehtonen (1988) found that IC patients appeared to have less effective coping strategies in dealing with ordinary life stress, as well as being more externally controlled. Similarly, IC patients were found to be less assertive and tended to value the opinions of others more than trusting their own viewpoints. They also scored higher on hostility, experienced more sexual problems and were more immature in personality development as noted through Rorschach assessment.

Schwartz (1987), speaking at the National Institutes of Health in Bethesda, Maryland, addressed the psychological aspects of interstitial cystitis, noting that a database examining any relationship between psychological variables and IC symptomatology is non existent. He empathized with IC patients in terms of feeling isolated and in coping with this problematic disease. Schwartz (1987) suggested that being told that there is possibly no cure, and that any relief from treatment is at best temporary, could

certainly result in panic, or a form of hysteria, or at the very least contribute considerable stress to an individual's life.

Schwartz (1987) supports a bio-psychosocial model with respect to the development of interstitial cystitis. Such a paradigm focuses on the initiation of this syndrome through a combination of life stresses, along with limited coping resources. Added to this are the amalgamation of genetic vulnerability, along with something happening environmentally (such as infection, an allergen, or some trauma event).

Borysenko's (1984) synopsis of a disease susceptibility model complements Schwartz's (1987) contention that environment (as a result of viruses, bacteria, chemical pollutants, some food ingredients and/or additives), genetic predisposition (including the inherited tendencies to weakness in certain bodily tissue or organs) and behavioral factors (primarily states of mind) may interact in various combinations and degrees to initiate a disease process.

The aforementioned series of events may be the impetus triggering immune suppression, which in turn may give rise to the pathogenesis of interstitial cystitis, thereby initiating the onset of symptoms. The symptoms stimulate attentiveness to bladder distension, which prompt a pattern of increased frequency, discomfort, pain and considerable anxiety, because of the painful and unrelenting symptoms.

A cycle may be set in motion whereby the individual experiences pain, discomfort and anxiety which in turn may stimulate muscular

contraction and further pain. This process in and of itself, may create additional anxiety and fear (LeCrone, 1979) which perpetuates a vicious and unfortunate circle . Difficulty in obtaining the appropriate diagnosis, along with the limited support and resources to contend with such a complex condition, can further fuel a state of extreme state anxiety and stress.

It must be remembered that the human organism continually strives to maintain a sense of order and homeostasis. Antonovsky (1984) states it this way:

> Homeostasis is occasionally disrupted by microbiological, physical, chemical and/or psychosocial stressors, vectors or agents. Regulatory mechanisms -neuropsychological, immunological, endocrinal - come into play in the organism's effort to restore homeostasis. Sometimes these mechanisms are inadequate and disease results (p. 114).

Perhaps interstitial cystitis patients experience more than just occasional disruptions in homeostasis. It may be that poor coping skills, irrational or negative thinking, or incessant stress and anxiety, exhaust the resources of the body, such that the weakest organ (the bladder in this case) falls prey to the disease process. Genetic vulnerability as well as environmental factors are also key components in disease onset.

The following diagram, based upon Joan Borysenko's (1984) model, depicts the possible interrelationship of a number of factors as they may relate to the disease, interstitial cystitis:

GENETIC VULNERABILITY

- vulnerable organ
  BLADDER

ENVIRONMENTAL FACTOR

Trauma:
- pelvic surgery
- bladder distention
- allergen
- food additives
- chemical pollutants or irritants

BEHAVIORAL FACTORS
-poor coping style in dealing with stress
-anxiety
-illogical or negative beliefs
-external locus of control
-pessimistic outlook
-stressful events prior to onset
-repressing feelings

Figure 1

The Mind-Body Connection and Illness

Psychological factors are frequently implicated as contributing to predisposition, onset or the course of many physical diseases. Psychosomatic medicine has witnessed a thrust in published research, exploring the interaction between disease, thoughts, feelings, behavior and the all embracing power of the mind.

Researchers, for instance have examined the relationship of attitudes and emotions on health (Grace & Graham, 1952; MacLean, 1949) the effects of chronic stress and negative life events on the immune system, (Saranson, Saranson & Johnson, 1985); the effects of emotions on physiological functioning (Antonovsky, 1979; Kobasa, Maddi, & Kahn, 1982); the interaction of cognitive and psychosocial factors such as stress, anxiety and learned helplessness on the immune system, via hormones and peptides (Fox, 1983; Korneva, Klimenko & Shkhinek, 1985) and the idea of the body as an analogy or metaphor for psychological health (Almy, Kern, & Abbot, 1950; Bull, 1945; Groen, 1947).

Similarly, numerous researchers have demonstrated mind-body links with respect to a variety of illnesses. The connection between cancer and psychological influences has long been noted by perceptive physicians. Mettler and Mettler (1947) reported that Galen, in the second century, described breast cancer as occurring in women evidencing a melancholic rather than saguine personality. Other physicians have observed that the growth and increase of cancer was often associated with deep anxiety, deferred hope and

disappointment, and the inability to express anger and fear.

More recently, researchers such as Wirshing et al., (1982) and Scherg, Cramer, & Blohmke (1981) related affective stance and breast tumors, while Mastrovito et al., (1979) investigated this factor with gynecological tumors. Kissen (1963, 1967), Grossarth-Maticek, Kanazir, Schmidt & Vetter, (1982, 1985) and Grossarth-Maticek, Kanazir, Vetter & Jankovic, (1983) investigated the mind-body continuum in connection with lung malignancies and heart disease. A relationship between depression and the development of uterine cancer was noted by Schmale and Iker (1966a, 1966b).

While more contemporary studies have characterized the cancer-prone person as holding in negative emotions, avoiding conflict, assuming a generally unassertive stance in life and not always getting their needs met, there have been some methodological difficulties and problems with sample sizes.

Eysenck (1988) contends that previous studies linking personality and illness have been clouded with uncertainty due to the lack of "large-scale studies in which personality traits are determined first and the people under investigation are then observed for many years" (p. 30). This would allow researchers to objectively verify which individuals become ill and with what illness.

Grossarth-Maticek et al., (1985) reported on their prospective studies in Yugoslavia, which commenced in the 1960's. Large random samples of subjects completed short questionnaires (which gleaned a propensity towards rational and anti-emotional behavior,

hopelessness and helplessness, and an absence of angry responses to traumatic life events) and participated in lengthy interviews.

From the questionnaire individuals were categorized into one of four groups: Type I cancer prone; Type II coronary heart disease prone; Types III and IV generally healthy individuals who were able to deal with stressors in a health promoting fashion. Smoking, drinking, physical health status and other characteristics were chronicled, along with the personality factors.

Analysis of these data every ten years or so, has shown that it was possible to predict death from cancer in the sample to an accuracy of 50 percent. According to other researchers this predictive acumen is at least six times higher than is a prediction from the factor of smoking. Of note were the statistics indicating that for Type I individuals, almost fifty (50) percent died of cancer, and fewer than ten (10) percent died from heart disease; approximately thirty-three (33) percent of the Type II individuals died from cardiac disease, and only twenty (20) percent of cancer; and in the Type III and IV grouping very few deaths were recorded.

While there appears to be a close connection between body-mind and disease onset, further prospective studies will be needed to verify in a substantive way, the role of personality attributes, stress and trait anxiety in disease process.

Moos and Solomon (1964) reported that the advancement of rheumatoid arthritis is closely connected to personality, while Baker and Brewerton (1981) found anxiety type stress which created

negative feelings prevalent in over half a group of female arthritic patients three months prior to onset.

McIntosh et al., (1983), contend that "whereas stressful events alone are not associated with ulcer, such events occurring in the life of an already anxious person could be ulcerogenic" (p. 949). Early studies of ulcerative colitis patients (Groen, 1947) pointed to certain character traits with some prior emotional conflict before onset.

Mind-body research seems to be gaining support for the close association of psyche and soma. As the Indian pundit, Mahabharata philosophized over 4000 years ago, "there are two classes of disease -bodily and mental. Each arises from the other, and neither exists without the other. Mental disorders arise from physical ones, and likewise physical disorders arise from mental ones" (Eysenck, 1988; p. 35).

Research is demonstrating that the brain and its highly sophisticated communication network is the basis of all body-mind interactions. As Eileen Growald (1985) states, "if we can augment our knowledge and understanding of how we communicate inside, we can help ourselves to health" (p. 10).

The coming years may prove that positive attitudes and emotions, the beliefs we hold, and our lifestyle are indeed central determinants to well being. In all disease process there is a need for collaborative efforts to clarify the nature of, and appropriate treatment methods for individual patients. Collaborative studies of

interstitial cystitis must also be initiated (Holm-Bentzen & Lose, 1987).

Improved understanding of the inherent psychological and physical aspects of the syndrome (IC), is seen to be an essential prerequisite for rational treatment of these often very disabled patients (Holm-Bentzen & Lose, 1987). Therefore, within this study several questions were addressed, with regards to the possibility of a relationship between certain psychological attributes and the bladder disease, interstitial cystitis.

Studies Linking Thought and Immune Functioning

Psychoneuroimmunologists have demonstrated through animal and human studies, how the immune system can be influenced by thoughts and emotions. Even so, there still remains considerable debate as to the role of the mind in illness.

Ader and Cohen (1982), and Gorczynski, Macrae, and Kennedy (1982) pioneered some exemplar animal studies in the field of psychoneuroimmunology, revealing evidence that the immune system can indeed be conditioned, and that it is inextricably linked to the Central Nervous System. Ader and Cohen (1982), successfully applied Pavlov's classical paradigm by conditioning mice to decrease their production of antibodies which were attacking their own tissue, causing an autoimmune disease much like Lupus.

The mice were injected with an immunosuppressive drug which was paired with a drink of saccharin solution. Following an appropriate

conditioning period, the saccharin injections were then substituted for the drug cyclophosphamide, which relieved symptoms by reducing the antibodies attacking the tissue of the mice. The conditioned mice receiving the saccharin and associating it with the drug, exhibited greater survival and slower development of symptoms of lupus than did the control animals.

This preliminary research paves the way for new methods of studying individual differences in experiences that shape the complex interrelationships among personality, stress, immune function and health.

Ader (1983), Locke and Colligan (1986) and Locke et al., (1984) have shown that the mind is continually modulating the immune system. Indeed the immune system has now been recognized as a third regulatory system of the body, on equal par with the autonomic nervous system and the endocrine system (Rossi, 1986). Numerous connections between the nervous system and the immune system indicate mind modulating influences by resisting or becoming susceptible to disease (Ornstein & Sobel, 1987).

Experimental and clinical studies have been reported in which the psychological factor of stress (Palmbad, 1985; Stein, Keller, & Schleifer, 1985) has been found to influence the onset of disease processes. Indeed it has been found that the immune system can be very negatively affected when the individual is under prolonged and unremitting stress (Bernstein, 1971, 1973).

Kiecolt-Glaser et al., (1985) report evidence supportive of the contention that depression may hinder the ability of cells to renew damaged DNA, thus increasing susceptibility to damage by environmental carcinogens. Again, the influence of the psyche on physiology appears to have considerable impact.

Schwartz's (1987) biopsychosocial model of the development of interstitial cystitis, points to a similar connection. He views some environmental happening (infection or another event, possibly some carcinogen) along with life stress and lack of coping skills, as all contributing to the initiation of this condition.

Edwards, Bucknall, and Makin (1986) have similarly responded to the need to determine the etiology of this condition and hypothesized that sepsis, or a poisoned state of the system due to infection, or some trauma to the bladder leads to the discharge or alteration of an antigen which may produce antibodies. This process ravages the bladder as a cycle of bladder damage, inflammation and eventual fibrosis is set in motion.

A predominant theme underlying much of the present research is that stress, emotional disturbance, and failure to adapt can enhance vulnerability to disease through immunosuppression. This is particularly significant in conditions associated with immunologic mechanisms such as autoimmune diseases and infection.

Several researchers have suggested that interstitial cystitis be regarded as an autoimmune disease (Edwards, Bucknall, & Makin, 1986 Jokinen, Alfthan, & Oravisto, 1972; Oravisto, 1980; Silk, 1970).

Campbell's Urology (1986) however questions this linkage, but admits the difficulty in singling out a unitary cause.

At this time researchers have suggested that psychoneurotic, endocrinologic, inflammatory (including autoimmune), neurogenic, lymphovascular, and infectious factors may precipitate the development of interstitial cystitis (Messing, 1986).

Further medical and laboratory research is needed to pinpoint more distinctly, the etiology of interstitial cystitis. Therefore, this study sought to investigate several specific psychogenic factors referred to in the urological literature.

It may indeed be reasonable to assume that there is a relationship between the psychological characteristics of trait and state anxiety, stress and/or an external locus of control and the disease interstitial cystitis.

Specific Psychological Attributes and Illness

The essential factor in the relationship of stress to altered immunity in humans, is the adaptive capacity of the individual. This is primarily influenced by one's perceptions, illness behavior, the habitual ways of thinking and behaving, as well as coping styles.

Persons challenged by an illness, have been compared to athletes challenged with competition, in that both must call upon all of their physical, mental and emotional resources in order to conquer the challenge or task at hand (Achterberg, 1985). This may include changes in lifestyle, beliefs and attitudes, relationships as well as the overall emotional state of the individual.

The close connection between mind and body has been demonstrated in a multitude of ways. Jordan and Lenington (1979) looked at how images can be interrelated with an individual's behavior, attitudes and beliefs in producing physiological changes. They confirmed that the recall of early negative images in one's life can produce changes in respiration, eye movement, heart rate and galvanic skin response.

Similarly, the mind-body association may be witnessed in daily living through response to any "fight or flight" stimuli. Quickened heart rate, rapid breathing, stomach tied in knots and excess sweating are all hallmarks of the body reacting physiologically to such situations. It is important to note, however, that the reaction can be the same whether the event actually occurs in the external world or in one's mind.

Rossi (1986) points out that there are recent data indicating a complex mind-body relationship between the role of the central nervous system, early life experience, emotions and learning in modulating the immune system.

Thoughts and feelings can precipitate a complex series of events which result in rather profound biophysical changes even at cellular levels (Woolley-Hart, 1979). Information from thoughts and feelings are sent to the mid-brain, which in turn relays it to the hypothalamus, then to the centers controlling the autonomic nervous system, and on to the periphery via the spinal cord.

The hypothalamus controls the balance of the autonomic nervous system between sympathetic and parasympathetic activities by monitoring information from thoughts, feelings, internal organs, and of course the five senses. As a result, the autonomic nervous system connects the mind with every cell in the body, such that a thought held in the mind affects the hormonal balance, blood flow, and metabolism. Research during this last decade has indicated that it is possible to shift the hypothalamic balance toward parasympathetic activity (Woolley-Hart, 1979).

An organ of adaptation, the brain constantly clarifies data received from its external and internal environment, matching it to the model it has created of the world (Ornstein & Sobel, 1987). Reality for bodily organs then, could be what the mind perceives as reality, and this is founded upon the beliefs and attitudes we hold.

Learning to be more logical and rational in thought and perception during times of stress and anxiety, may well inhibit the body's production of stress chemicals which can affect the development of illness (Justice, 1988). Brain chemicals are often altered when individuals feel they are not in control, and this in turn can lead to depression and hopelessness (Ahluwalia, Zaacharko & Anisman, 1985; Gallagher, 1986; Siever & Davis, 1985; Weiss et al., 1979). Assisting individuals to change distorted patterns of thinking can produce positive chemical changes within the brain (Paul, 1986).

Norman Cousins (1979) recovered from the painful and life threatening condition, ankylosing spondilitis, by taking control of

his health and life, working in partnership with his physician and by adopting a rational and happy attitude. As Cousins' environment and attitude changed there was a corresponding drop in his sedimentation rate, a measure of infection in the body.

Some twelve years later a scientific explanation was proposed (Levine, Gordon & Fields, 1978), when it was discovered that the brain secretes a protein-like material called endorphins. Endorphins, which are produced in the body in response to laughter and a happy attitude, were found to be as potent as morphine in killing pain. This strongly implied that an individual's mental attitude can have a very direct bearing upon the control of pain.

The beliefs we hold about ourselves and the world, can have considerable impact in terms of our overall happiness and health. Stress and anxiety are not the result of stressors per se, but rather, the result of the way in which we think about and appraise an event based upon our belief system. This interactional perspective of stress is supported by Ellis (1978) as well as other researchers (Hiebert, 1983, 1985, 1987; Kasl, 1984; Magnusson, 1982).

The beliefs and attitudes we have are unconscious as well as conscious, and as a result they have a profound effect on all of our behaviors. Attitudes, therefore may enhance health or contribute to "dis-ease". Since the subconscious mind plays such an important role in our lives, an obvious question arises, 'can we influence our subconscious mind?' One way is through our thoughts, for what we

think has a tremendous influence over our subconscious (Achterberg, 1985; Brown, 1980; Rossi, 1986), and another way is through visualization (Rossman, 1984, 1988; Simonton, Simonton & Creighton, 1978).

Cardiologist, Robert Eliot (1984) of the National Center of Preventive and Stress Medicine, furnishes an interesting view on how important it is to keep stressful situations in perspective. He believes that much of what we disturb ourselves with is really about insignificant, trivial, or "small stuff". The self talk we engage in twenty-four hours a day, awake and in sleep, is often filled with illogical and untrue attitudes which often cause considerable upset emotionally and physically.

Talking to ourselves, gaining insight, looking at our options, making decisions as to whether to "fight-or-flee", or accept what we cannot change, is sometimes the best prescription or advice we can follow. The opposite, creates considerable stress and anxiety, which if unchecked can predispose an individual to "dis-ease" and possible illness.

Beliefs and expectations have biological consequences, so do attitudes. Research has shown the implications physiologically in terms of the definite neuroendocrine and neurohormone accompaniments to a positive happy mood and to a strong positive attitude. Rossi (1986) suggests that Norman Cousins is a living example of the effect positive emotions and logical beliefs can have upon the biochemistry of the body in facilitating rejuvenation and health.

On a cautious note, Benson (1984) emphasizes that there are medical limits to what even the strongest of positive beliefs can achieve. We all must die, and we all will experience some illness or discomfort at some time in our lives. He points to the fact that physicians will likely be more successful than the use of our belief system in at least 25% of all ailments, through the application of specific medical remedies such as medication or surgical procedures.

There remains however, a sizeable 75% of health concerns wherein the power of our thoughts, beliefs, and our sense that we can exude control over what is happening to us, can be powerfully utilized to effect healing (Benson, 1984).

Thoughts and beliefs have been shown to impact significantly on the total physiology, and therefore there may a real mind-body connection in the cycle of this complex syndrome, both in its inception and continuance.

Anxiety, Stress, Locus of Control and Illness

Baker in 1755, suggested that nothing so saps and weakens one's constitution as anxious thought. Rossman (1988) similarly believes that worry is a universal form of imagery, affecting the health of innumerable people on a daily basis.

For many, the physical evidence of stress begins with a moderate degree of worry, which over the course of time becomes a form of mental anguish. As a result of prolonged periods of mental distress, anxiety and thwarted attempts to cope, the body's

physiological functioning becomes disturbed, health is enervated, and an organ like the stomach, colon, or bladder may become involved.

Stress, suggests Barbara Brown (1980) always involves the self and how one's self and one's beliefs, attitudes, feelings and perceptions relate to social interactions (p. 91). This clearly involves the meaning attached to interactions with others.

A number of intangible mental processes may precipitate stress, which over the long term undermine health. First, if one's perceptions and expectations about a specific situation do not correspond, stress may be the result, particularly if there are no effective cognitive resources available to cope.

As the mind focuses on the gap between one's perceptions and expectations in a given instance, a problem is noted and worry ensues. Uncertainty, apprehension and anxiety in not being able to successfully solve a problem may result in physiological changes.

Rumination is often seen as a circular kind of worry where the nuances and complexities of a problem or situation are played over and over again in the mind, without successful resolution. Brown (1980) suggests that as rumination continues, so do the adverse effects of worry on the body's physiology. The uncertainty about answers continues to keep the body aroused, the inability to find answers leads to frustration and intensifies apprehension and anxiety. A cycle of fear, anxiety, worry, uncertainty and insecurity is perpetuated, and this absorption with pessimistic or

negative thoughts prevents the mind from drawing upon other information which could help solve the concern or problem.

It may be that many interstitial cystitis patients become caught in such a cycle where they are unable to tap resources or pertinent information which could provide a sense of control, feelings of hope or a sense of calm. Providing interstitial cystitis patients with relevant data regarding their condition, the effects of traditional and adjunctive treatments and the kinds of strategies they can implement to help themselves may be particularly helpful in problem solving with respect to their physical condition and how it might best be treated. At the same time, having access to necessary information and available resources may reduce stress considerably.

Kobasa, Maddi and Courington (1981) conducted a study of 200 executives during a stressful AT&T reorganization. They were interested in why half the executives experienced numerous illnesses while the other half displayed no physical complaints. Individuals who remained healthy, had a different view of the stressful event, such that they used optimistic cognitive appraisal to see change as a part of life, as well as a challenge and opportunity for growth. The sense of internal cognitive control allowed these individuals to decide what impact the change/stressors would have upon their lives.

This transformational coping, suggest Maddi and Kobasa (1984), enables individuals to transmute or modify stressful events so that they are less anxiety provoking. This was accomplished by interacting with the event such that it was viewed optimistically in

terms of outcome, and as a result, some decisive action was taken to resolve the "challenge".

A basic proposition of psychological "hardiness" studies underlines the importance of the view we hold of stress, as well as the attitudes and beliefs we have with regard to the control we assume in dealing with life's challenges. It would seem that how we cognitively appraise events in our lives, may have important and permeating implications and repercussions on our overall health.

Like the preceding researchers, Antonovsky (1987) also sought to examine what personality characteristics constitute hardiness in the face of sometimes overwhelming demands. Antonovsky (1987) suggests a sense of coherence (SOC) is the central and crucial component of personality which allows a person to move closer to the health end of what he calls the "health ease/dise-ease continuum" (p. 3).

Sense of coherence is essentially an all encompassing feeling of confidence in oneself, that no matter what demands arise in one's internal or external world, they are merely challenges which can be successfully met by accessing the appropriate resources at the most useful or opportune time.

It may be that many interstitial cystitis patients lack a sense of confidence or control in accessing internal and external resources that would assist them in managing the challenges of their dis-ease. Antonovsky (1987) notes that individuals who do not have a strong sense of coherence tend to "see chaos, to feel hopeless and burdened" (p. 186).

Pessimism, Learned Helplessness and Explanatory Style

A number of prominent researchers have examined pessimistic explanatory style as a risk factor in illness (Alloy, Peterson, Abramson & Seligman, 1984; Kamen & Seligman, 1987; Peterson, 1988; Peterson & Seligman, 1987; Peterson, Seligman & Vaillant, 1988; Seligman & Schulman, 1986; Tennen & Affleck, 1987).

Early investigations into learned helplessness in animals and humans indicated that exposure to uncontrollable stress created a feeling of giving up and a sense of helplessness and hopelessness resulted (Schmale & Iker, 1966; Sklar & Anisman, 1979; Visintainer, Volpicelli, & Seligman, 1982).

Kamen and Seligman (1987) suggest that a sense of control results from an established explanatory style which may either enhance health or contribute to a disease process. Essentially, our explanatory style is rendered from early socialization experiences as well as encounters with loss (Peterson, Seligman & Vaillant, 1988).

In brief, the aforementioned researchers contend that a person who repeatedly views or cognitively appraises life with an internal, stable and global style, tends to attribute the cause of a problem to themselves - an internal attribution. This is followed by an enduring or stable belief that life will continue to be this way, which results in an encompassing or global feeling that nothing will ever work out.

Cognitive appraisals such as these, result in the emergence of a

pessimistic explanatory style, which erode feelings of control in life, and are deleterious to health (Peterson, 1988; Peterson & Seligman, 1987; Peterson, Seligman & Vaillant, 1988).

Unfortunately, when a person cognitively views the world with a strictly internal attribution, little consideration is given to the fact that there may be one or more external factors which indeed have played a role or contributed to a difficult situation or problem.

Peterson, Seligman and Vaillant (1988) suggest that the habitual way one cognitively appraises or explains bad events has serious implications for future health. Passivity, pessimism and depression may precipitate disease, suggest Peterson and Seligman (1987), although the pathways through which this may occur are still in need of study.

With a pervasive feeling of hopelessness there is the expectancy that no matter what action is initiated, it will have little or no impact upon outcome (Scheier & Carver, 1987). If we typically respond to challenging life events with feelings of helplessness and hopelessness, then we disturb cortisol levels which cause immunosuppression (Everly, 1989). Feelings of helplessness-hopelessness are known to exhaust the brain's resources of norepinephrine, a chemical which is essential to feelings of well-being, health and contentment.

Bresler and Rossman (1988) provide a vivid illustration with regard to how thoughts impact and produce physiological changes: If

merely thinking about a lemon precipitates salivation, then what is the impact of persistent thoughts and feelings of helplessness-hopelessness on the body?

Do women experiencing interstitial cystitis, have higher levels of anxiety, more negative thought patterns, an external locus of control and a specific coping style? And if so, could this possibly predispose them to cognitively appraise or react to situations in ways, which over time could impact physiologically? Could it be that high levels of anxiety, a certain coping style, and sensing little control over one's life situation, combine with other important genetic factors to set in motion the conditions for onset of interstitial cystitis? These were some of the questions central to this study.

The recent growth of research into the mind-body connection, has demonstrated how our immunity can be influenced by our cognitions (thoughts, beliefs and attitudes), and hormonal changes, which are produced as a result of poor coping strategies or by direct effects of our central nervous system.

Cousins (1981) suggests that:

> The belief system is often the activator of the healing system. It represents the unique element in human beings that makes it possible for the human mind to affect the workings of the body. As human beings learn more about the way their thoughts and attitudes affect their internal chemistry, they will discover the greatest factor in their evolution, the governance of their own totalities (p. 208).

While research of the mind-body link in disease process continues, it appears that there are some positive indications of a very close connection. Research into the psychosomatic aspects of such illnesses as heart disease, cancer, colitis, and rheumatoid arthritis to name a few, has begun and continues to grow.

In terms of interstitial cystitis, limited and conflicting data make this a particularly problematic condition for both physician and patient alike. A further understanding of the etiology is required, and in this regard, the complex psychosocial components must be addressed.

The Interstitial Cystitis Associations of California and New York have established a lobby in Washington to pressure the U.S. government to fund projects through the National Institutes for Health (NIH). At this time the NIH is calling for research proposals specifically addressing interstitial cystitis, indicating that a need for further research has been generally recognized.

This study then, acknowledged the need for research to investigate factors which may possibly play a role in the very complex disease process of interstitial cystitis.

Concluding Comments

In consideration of the mind-body research presented, along with the literature review of interstitial cystitis, it seems reasonable to hypothesize that in women:

(1) there is a positive relationship between the possession of state and trait anxiety and the disease interstitial cystitis.

(2) there is a positive relationship between the possession of irrational beliefs and the disease, interstitial cystitis.

(3) there is a positive relationship between an external locus of control and the disease interstitial cystitis.

(4) there is a positive relationship between external health locus of control and the disease interstitial cystitis.

(5) there is a positive relationship between specific behavioral health attitudes and the disease interstitial cystitis.

CHAPTER 3

Methodology

A total of 166 persons were included in the original sample in this study, which was made up of three distinct groups: (1) an Interstitial Cystitis (IC) group, (2) a Urinary Tract Infection (cystitis) group and (3) a Random Control group.

General demographic information was collected from all participants. The IC group, however, completed a more comprehensive questionnaire in order to provide detailed data concerning specific medical and personal history.

All participants then completed a battery of paper and pencil inventories measuring anxiety, irrational ideas, generalized internal-external locus of control, health locus of control in addition to a general behavioral health inventory.

In addition, interviews were conducted with 30 interstitial cystitis patients, in order to provide insight into this enigmatic condition.

A. The Sample

Interstitial Cystitis (IC) Group

Group one was made up of fifty-nine (59) diagnosed interstitial cystitis patients referred directly by urologists in Alberta and Ontario. The referring urologist obtained permission from her/his patient to forward the patient's name and phone number to the researcher. The researcher then contacted the patient to outline and discuss the nature of the study, as well as to provide an indication of the time commitment involved in this research. At that time, an appointment was made with the patient to complete the questionnaire (Appendix A and Appendix B) and participate in an interview (Appendix E).

There were twenty-two (22) Alberta referrals from as widely diverse communities as Edmonton, Red Deer, Calgary, Lethbridge, Medicine Hat and Drumheller. Another fifty patients from Eastern Canada were referred by Kingston urologist, Dr. Ramon Perez-Marrero. Out of this total of seventy-two (72) referrals, nineteen (19) patients from Alberta and forty (40) from Ontario actually participated in the study, representing a consent rate of 82 percent.

Within the total IC group, the age ranged from twenty-one years (21) to eighty-three (83) years, with a mean age of forty-eight (48) years. Only five males were referred with interstitial cystitis, of which three actually completed the questionnaire.

Urinary Tract Infection (Cystitis) Group

The second group was drawn randomly from patients who had been seen for urinary tract infection by Edmonton urologists Dr. W. Lakey and Dr. R. Boake. Selection was based on coded billings which indicated that these patients had consulted their specialist regarding a urinary tract infection within the preceding eighteen months. Questionnaires were mailed to fifty of these randomly selected patients (Appendix A).

A total of forty six (46) questionnaires, two (2) males and forty-four (44) females, were returned from the Urinary Tract Infection group indicating an excellent 92 percent return rate. Patients within this group ranged in age from eighteen (18) to seventy-five (75) years of age, with a mean age of thirty-nine (39) years.

Random Control Group

The third group was drawn from a random sample obtained from the Henderson Directory. Initially, ninety letters (90) were mailed out to persons selected at random, requesting their assistance in the study (Appendix D). Ten (10) letters were not able to be delivered and were returned by the Edmonton Post Office. Eighty (80) questionnaires were then mailed out, and a total of sixty-two (62) were returned for a good return rate of seventy-eight (78) percent. One questionnaire was incomplete and had to be discarded.

Responses were received from seventeen (17) males and forty-four (44) females, and ranged in age from twenty-two (22) to ninety (90) years. The mean age within the group was forty-two (42) years.

Adjusted Sample

As data collection proceeded, it became apparent that a disproportionate number of females to males were being referred in the IC and Urinary Tract Infection groups. In fact, of the one hundred and five (105) persons who participated in the study from these two groups, only five (5) were males. This number is in line with a statistic quoted by Hanno (1989), which indicated that interstitial cystitis occurs at least ten times more often in women.

As there were difficulties in obtaining large enough samples of males in both the Urinary Tract Infection and IC groups, a decision was made to limit the final analysis to the female participants only. This resulted in a total sample of One hundred and forty-four (144) women: fifty-six (56) in the IC group, forty-four (44) in the Urinary Tract Infection group and forty-four (44) in the Random Control group.

B. Procedure

In May 1989, the research proposal and questionnaires were submitted for approval to the Ethics Committees at both the Walter C. MacKenzie Health Sciences Center and the Department of Educational Psychology at the University of Alberta.

Following ethics approval, Dr. W. Lakey corresponded with all the urologists in Alberta to make them aware of this study involving interstitial cystitis patients. The intent of the study was summarized, as was a request for the support of urologists in referring appropriate patients.

The researcher then followed up this initial correspondence with a form letter to the Alberta urologists outlining the study in more detail. Names and telephone numbers were requested for individuals diagnosed with interstitial cystitis. Uniformity of diagnosis was stressed, particularly to ensure that cystoscopy with bladder distention occurred, in order to confirm hemorrhages on the bladder walls. (The letter circulated to physicians across the province is included in Appendix C).

Interstitial cystitis patients in Alberta were contacted by phone following referral from their urologist. The researcher made arrangements with each individual to schedule times for completion of the inventory. Where time permitted, patients participated in a structured interview. Data collection began in January, 1939 and continued until completion of this phase in October, 1989. At the

outset, Alberta referrals were very sporadic, however as they were received the researcher travelled throughout the province to administer questionnaires and interview the IC patients. Nine (9) persons from the Alberta IC population came from rural towns or communities throughout the province.

Until only recently, interstitial cystitis had been considered quite rare. This, along with a dearth of diagnostically confirmed cases precluded the possibility of large samples in any one area of the country. Since referrals throughout the Province of Alberta were limited, this prompted the researcher to look for additional IC patients in other areas of Canada.

During the initial phase of the study, the researcher had the occasion to contact Dr. L. Nyberg, Director of Urology Programs, National Institute of Diabetes, Digestive and Kidney Diseases in Bethesda, Maryland. Dr. Nyberg indicated that Canadian urologist Dr. Perez-Marrero had published a number of journal articles on interstitial cystitis and might possibly be of assistance in finding further IC patients.

Telephone contact with Dr. Ramon Perez-Marrero, confirmed that this Kingston urologist had a diagnosed population of interstitial cystitis patients, which he had chronicled over the past five years. Ethics documents, along with sample questionnaires were then forwarded to Dr. Perez-Marrero in order to formalize and finalize arrangements to include a number of diagnosed interstitial cystitis patients from Kingston and the surrounding areas.

With the assistance of Dr. Perez' research nurse, Laurel Emerson, these patients were contacted to obtain their consent to be involved in the present study. At the same time she scheduled appointments for completion of the questionnaires and for interviews. In August 1989, the researcher travelled to Ontario and spent five days at the Kingston General Hospital collecting data from forty IC patients, all of whom lived within a 100 mile radius of Kingston.

Early in September, 1989, arrangements were made to obtain a sample for the Urinary Tract Infection (cystitis) group. This group was drawn randomly from patients who had been seen for urinary tract infection by Edmonton urologists Dr. W. Lakey and Dr. R. Boake. Selection was based on coded billings which indicated that these patients had been treated for bacterial cystitis within the preceding eighteen months.

After random selection from the files, they were contacted by the urologist's receptionist to obtain their consent and determine their willingness to participate in the study. Only two (2) persons declined to take part.

Questionnaires were mailed to those patients who indicated a willingness to cooperate. The importance of completing all portions of the questionnaire prior to returning the test battery, was stressed. Anonymity was afforded each person, in that no names or identifying codes were utilized.

Beginning in June, 1989, the researcher set out to secure a healthy population of individuals from family physicians in Edmonton, which it was hoped would make up the control group. Contacts with a number of general practitioners were made, and interest was expressed in the study. Over the course of several months however, it was found that referrals were insufficient.

It was also noted, that many of the referred patients did in fact have a chronic health concern which they had not expressed to their physician at the time of referral to this study. Upon raising this issue, one family practice physician suggested that more time must be allocated to asking patient's how their life was going and whether they were encountering any physical effects of stress. Time pressures, along with other demands, made it difficult for physicians to routinely focus on the criteria of the study.

A recent investigative study by Hanno et al., (1990) similarly attests that it "virtually is impossible to amass data on truly normal people" (p. 278). After considering this impasse, the decision was made to utilize a random sample.

One hundred and fifty randomly selected numbers between 1 and 1000 were generated by computer process. These were then utilized to select page numbers from the Henderson Directory. The line and column for each page were selected at random, in the same manner. Initially, a total of ninety-eight (98) households was selected for contact. Following this, a letter of introduction outlining the study and explaining the need for support was forwarded to each of

these households. Ten (10) of these letters could not be delivered, as the persons had moved, and were returned by the Post Office. (The letter mailed to the random sample is found in Appendix D).

Eight to ten days later, the researcher telephoned the remaining eighty-eight (88) households. At this time any questions or concerns were answered, and the individual who answered the telephone was asked whether he or she was willing to participate in the study. From this initial contact only eight households declined involvement. Reasons for refusal included: "immediate family problems/stresses", a belief that "there is too much free information floating around", and "not interested!".

Eighty (80) questionnaires were then mailed to those individuals who indicated a willingness to cooperate. The importance of completing all portions of the questionnaire prior to returning it was also emphasized. Once again, anonymity was also afforded each person, in that no names or identifying codes were utilized.

Pilot Study

In order to ascertain the appropriateness of certain inventories, and to select measures which would yield information concerning specific personality characteristics and traits with respect to interstitial cystitis, a pilot study was conducted. This involved a small number of in-depth, semi-structured interviews which were conducted during the winter of 1988-1989. Viewed as a preliminary inquiry, these interviews produced a picture of

common themes and concerns of IC patients which could then be noted and considered in conjunction with pertinent material collected from the literature review.

Five (5) females, who had been diagnosed with interstitial cystitis, were contacted and agreed to participate in this preparative phase. A ninety minute interview provided the format to discern common themes as well as give direction to the more formal study to follow. The participants ranged in age from forty-five (45) to sixty-three (63) years. An eagerness to assist in collecting research data on this difficult condition was verbalized by each subject in the pilot study.

Family history, specific and pertinent occurrences during their growing up years, personal methods of dealing with stress, childhood messages gleaned from their parents through overt or covert teachings, and how interstitial cystitis patients typically deal with feelings and anxiety were addressed in the structured interview (Appendix E). As well, each woman was asked about her sense of power in controlling events and happenings in her life. By surveying these IC patients through this modality, it was possible to ascertain some of the psychosocial factors which could have an impact upon this disease.

It is interesting that Indianapolis urologist, Dr. Philip Mosbaugh chose to describe interstitial cystitis as a "benign condition but a malignant problem" (Rose, 1989, p. 51). Fortunately, due to an ever increasing awareness on the part of

general practitioners and urologists alike, more patients presenting with typical symptoms are benefiting from appropriate screening and diagnosis.

To date researchers have primarily examined pharmacological and surgical interventions in the treatment of this disease. The complexity of the illness and limited research integrating other disciplines, have resulted in this exploratory study designed to address whether psychosocial correlates play a role in onset or exacerbation of symptoms.

C. Instruments

All participants completed a battery of paper and pencil inventories measuring state and trait anxiety, irrational ideas, internal-external locus of control and health locus of control, along with a general behavioral health inventory.

The majority of interstitial cystitis patients completed the inventories, either at the University of Alberta, a designated location close to their home, or at Kingston General Hospital. The Urinary Tract Infection group and the Random sample completed the questionnaires at home and returned them by mail. In these instances, the importance of working through the inventories independently, was emphasized.

State-Trait Anxiety Inventory

The State-Trait Anxiety Inventory Form Y (STAI), includes separate self-report scales for measuring two distinct anxiety concepts: State anxiety (S-Anxiety) and Trait anxiety (T-Anxiety). For the purposes of the present study, both T-Anxiety and S-Anxiety were employed. The T-Anxiety portion of the STAI consists of 20 statements that ask subjects to describe how they "generally" feel. According to Spielberger (Robyak, 1986) trait anxiety is assessed by measuring the frequency at which anxiety is experienced and state anxiety by measuring the intensity of the emotional state at particular times.

The S-Anxiety scale also consists of 20 statements that evaluate how respondents feel "in a work situation", in accordance with instructions in the manual where the author suggests that "..when the STAI is administered for research purposes the examiner may wish to alter instructions for the S-Anxiety scale (Spielberger. 1983; p. 3).

Each STAI item is given a weighted score of one (1) to four (4). A rating of four (4) indicates the presence of a high level of anxiety for ten S-Anxiety items and eleven T-Anxiety items. A high rating on the other items indicates the absence of anxiety. Scores for both the S-Anxiety and the T-Anxiety scales can vary from a minimum of twenty (20) to a maximum of eighty (80). Scoring information may be found in the test manual (Spielberger, 1983).

Evidence of concurrent validity has been reported in a long series of research studies demonstrating a good correlation (.73 to .85) between the trait anxiety scale and other measures of trait anxiety. This research included comparisons with the IPAT Anxiety Scale (Cattell & Scheier, 1963) and the Taylor (1953) Manifest Anxiety Scale (TMAS). In the development of the STAI, individual items were required to meet prescribed T-Anxiety validity criteria in order to provide an operational measure of trait anxiety in accordance with the definition of the construct.

The test-retest reliability, or stability of T-Anxiety tends to be relatively high. Test-retest reliability ranges from .76 to .86 after 20 days to .73 to .77 after three months. For S-Anxiety,

test-retest reliability is lower, at .33 after three months. This is to be expected, from a measure assessing changes in anxiety arising from situational stress.

A high degree of internal consistency has been reported for the T-Anxiety scale, with Alpha coefficients ranging from .86 to .92 using the Kuder-Richardson 20 formula for normative samples.

The T-Anxiety scale has been used as a research tool for selecting subjects who vary in their dispositions to respond to psychological stress with different levels of A-State intensity (Lazarus & Opton, 1966). In clinical settings it has provided a means for evaluating which subjects who seek counselling are troubled by neurotic anxiety problems, and as a method of screening students for anxiety-proneness (Spielberger, Gorsuch & Lushene, 1984).

A comprehensive review of reliability and validity is provided in the State-Trait Inventory: A complete Bibliography (Spielberger, 1983), which lists over 2000 publications in which the STAI was used to measure anxiety.

Adult Irrational Ideas Inventory (AII)

The Adult Irrational Ideas Inventory by Davies and Zingle (1970), is based upon the eleven irrational beliefs of Albert Ellis (1962), as well as the Irrational Ideas Inventory (Zingle, 1965) developed for adolescents . Designed to measure the presence of illogical or irrational thinking, the (AII) is a 60 item scale. The

original form contained 99 items which were item analyzed and resulted in a final 60 item form of the most discriminating items.

Responses are recorded on a 5 point likert-type scale which ranges from strongly disagree to strongly agree. Statements have been worded such that strong agreement is sometimes scored high (5) and sometimes scored low (1). The authors purposefully utilized this format to prevent the effect of response set.

Reliability has been established by using both Kuder-Richardson split-half and test-retest procedures. Reliability estimates ranged from .74 to .78. Content validity assumptions are supported by its derivation from the I-I inventory (Zingle, 1965). Items for the AII were taken directly from the I-I item pool to construct the Adult Irrational Ideas Inventory. The concurrence of two judges familiar with Ellis' irrational beliefs, a review by Ellis himself, as well as subjection to item analysis also contributed to the content validity. Detailed information regarding the validity of the I-I Inventory is provided by Allen (1970).

The Internal-External Locus of Control Scale

The Internal-External (I-E) Locus of Control Scale is a well known and popular measure of Internal-External Control. It was developed out of the theoretical concept that the effects of reward or reinforcement on preceding behavior depend on whether the subject perceives the reward as contingent on his own behavior or independent of it. Generalized expectancies are then formed

throughout an individual's life, depending on his or her history of reinforcement. This results then, in the concept that individuals differ in the degree to which they attribute reinforcements to their own actions.

While Rotter (1966) views internality as the more positive state, other researchers see externality as also having some positive characteristics (Janzen & Beeken, 1973; Rodin, Rennart & Soloman, 1980). Both Rotter (1966) and Lefcourt (1976) however see internal control as indicative of self-determination while externality may be seen as closely tied to fatalism.

The I-E Scale is a 29-item, forced choice test, which includes 6 filler items intended to make the purpose of the test more ambiguous. Concurrent validity has been shown through correlations with other methods of assessing the same variable such as questionnaire, Likert scale, interview assessments and ratings from a story completion technique. The most significant evidence of construct validity comes from predicted differences in behavior for individuals above and below the median.

Results of a series of studies have shown that an individual who has a strong belief that she can control her own destiny is likely to: (1) be more alert to those aspects of the environment which will provide useful information for future behavior; (2) take steps to improve her environmental conditions; (3) place greater value on skill or achievement reinforcements and be generally more concerned with ability, particularly as it relates to failures; and (4) be

resistive to subtle attempt to influence her behavior, without her awareness.

Item analysis and factor analysis show stable and reasonably high internal consistency. Split half (.65 to .79) and Kuder-Richardson (.69 to .76) reliabilities are adequate for an additive test where items are forced choice and are not comparable. Test-retest reliability has been shown to range from .72 to .78 after one month to .55 after two months.

Multidimensional Health Locus of Control Scales

The Multidimensional Health Locus of Control Scales (MHLC; Wallston, Wallston, & DeVellis, 1978) are comprised of an 18 item self report instrument which measures three dimensions of locus of control as it pertains to health: internality of health locus of control (IHLC), powerful other health locus of control (POLC) and chance locus of control (CHLC). Specifically, the MHLC attempts to assess an individual's beliefs that their health is or is not determined by her/his own behavior.

The MHLC has two parallel forms (A and B), which are designed for repeated measures, or may be combined to create longer (36 items) and more reliable subscales. Since the present study obtained only one measurement, the latter method was adopted. When the parallel forms are combined to form 12-item subscales fairly high internal consistency reliability (.83 to .86) has been reported for each of the three subscales (Wallston, Wallston & DeVellis, 1978).

Winefield (1982) extensively analyzed the MHLC and reports the internal health locus of control (IHLC) and powerful other (POLC) subscales to be moderately homogeneous and reliable over seven months r= .58 and .76 respectively (p= <.001, one tail). Powerful other increases with age, and with acute disease.

Fairly good reliability has been established, by correlating MHLC scores with subjects' state of health. Alpha reliabilities range from .67 to .77 (Wallston, Wallston & DeVellis, 1978; p. 163). Concurrent validity has been shown by correlations with other measures of locus of control, including the Multidimensional Locus of Control Scales for Psychiatric Patients (Levenson, 1973).

Millon Behavioral Health Inventory (MBHI)

The only other reported study of personality factors as they relate to interstitial cystitis patients utilized instruments such as the Rorschach and the Lazare Personality Test (Keltikangas-Jarvinen, Auvinen & Lehtonen, 1988). Such instruments were developed or intended for use primarily with psychiatric patients. As such, they may present problems with regard to the appropriateness or content of the test items. The Millon Behavioral Health Inventory (MBHI; Millon, Green & Meagher, 1982), on the other hand was selected for use in the present study specifically because it was developed for non-psychiatric medical populations.

The MBHI consists of 150 true-false items designed for use in paper and pencil, or in computer format. Developed as a research

instrument, as well as an aid for clinicians and health care professionals, the MBHI can also be incorporated with treatment interventions. Four dimensions are addressed which can provide assistance in medical-behavioral planning. The following twenty (20) subscales are subsumed under the four dimensions below:

Basic Coping Style Scales

a. Introversive coping style

b. Inhibited coping style

c. Cooperative coping style

d. Sociable coping style

e. Confident coping style

f. Forceful coping style

g. Respectful coping style

h. Sensitive coping style

Psychogenic Attitudes Scales

i. Chronic Tension

j. Recent Stress

k. Premorbid Pessimism

l. Future Despair

m. Social Alienation

n. Somatic Anxiety

Psychosomatic Correlates Scales

o. Gastrointestinal Susceptibility

p. Allergic Inclination

q. Cardiovascular Tendency

Prognostic Indices Scales

r. Emotional Vulnerability

s. Life Threat Reactivity

t. Pain Treatment Responsivity

Millon, Green and Meagher (1982) and Schmidt (1981) note good psychometric properties with respect to reliability. Kuder-Richardson Formula 20 estimates range from .66 to .90 (median .83).

A variety of different and often homogeneous non patient as well as patient populations have provided correlational data. In this regard, the MMPI, the I-E Scale, the Beck Depression Inventory, Personal Orientation Inventory, Life Events Survey, Webber-Johansson Temperament Survey and the California Personality Inventory have been utilized and are reported in the MBHI Manual (Millon, Green, & Meagher, 1982).

In terms of test-retest reliability, Green (1982) reports that after four and a half months (4 1/2) months, the coping style scales show high test-retest reliabilities with most in the range of .77 to .88 (mean .82). Psychogenic, psychosomatic and prognostic scales also reveal high reliabilities averaging .85 with the exception of emotional vulnerability.

While specific elevated scale scores point to certain traits and behaviors, Millon, Green and Meagher (1982) note that interpretation of results is normally carried out by analyzing the constellation of profile scale scores, rather than focusing on one score. This

profile analysis would also be complemented by information gathered through additional instruments administered in a test battery.

Millon, Green, and Meagher (1982) indicate that although configurations vary in every setting, certain patterns may be found with greater frequency in settings that serve particular populations such as pain patients, surgical bypass candidates, renal dialysis patients, or oncology patients.

Familiarity with a specific patient group, such as interstitial cystitis patients for example, often fosters the ability to make distinctions and variations among patient's profiles which can assist in designing treatment plans conducive to holistic care.

Delimitations and Limitations of the Study

Research related to the psychosocial aspects of IC is indeed limited. As with any research study, an investigation within the mind-body domain as it specifically pertains to health, carries with it delimitations as well as limitations, which have a bearing on the total study. It is crucial that the reader be aware of these constraints in considering the results. It must also be remembered that because this was a relatively new frontier, this research was seen to be exploratory in nature, and therefore the results must be considered accordingly.

A. Delimitations

1. A very limited body of literature relating psychosocial factors to interstitial cystitis provided only minimal direction in terms of possible variables to investigate. For this reason, the scope of the study was delimited to the relationship of anxiety and IC, irrational beliefs and IC, locus of control and IC and specific behavioral health attitudes and coping style and interstitial cystitis.

2. With this in mind, caution must be exercised in the event that certain crucial variables may have been set aside or given only minimal consideration. In such instances, the recommendation

has been that these concerns be studied in further investigations (see Chapter 5).

3. The study was further delimited through the choice of instruments utilized to measure the various dimensions. Future research will need to expand on this initial study and examine with additional instruments, these preliminary findings.

4. The sample included only females. From the time research began to the completion of data collection, only three (3) male IC patients and two (2) male urinary tract infection patients actually participated. While each male completed the questionnaire and participated in an interview, this lesser number of males resulted in a decision to eliminate males entirely from the data analysis, and to delimit the study to women.

B. Limitations

Prior to commencing the research, certain limitations were recognized and addressed by the researcher and these are noted below. As well, there were unexpected limitations which occurred during this process which have also been discussed.

1. The subject selection process is a limitation. Urologists referred appropriate patients to the study. Following this, patients were contacted by the researcher to establish a time to complete the questionnaire and participate in an interview. In three instances, IC patients chose not to become involved in the research, after agreeing to do so in discussion with their urologist. This change in mind was expressed to the researcher either directly over the phone or through failure to appear at the time agreed to complete the questionnaire. It is perhaps interesting to note that of the three (3) IC patients indicating an unwillingness to participate, two (2) of them were young men. While these men initially expressed an interest in the study and verbalized the need for research which could provide better management and more effective relief of symptoms, it may be that embarrassment or a self consciousness in acknowledging this bladder condition, resulted in their decision not to become involved. Because the study included only women, it is not possible to generalize the results to all interstitial cystitis patients.

2. While guidelines have been set forth in the diagnosis of interstitial cystitis, there are gradations of the disease. Each patient with IC, may experience a different stage of the illness, as well as greater or lesser degrees of pain, urgency and frequency. The present study accepted all appropriately

diagnosed cases of IC. Within the sample there were newly diagnosed cases, as well as patients who had experienced this disease for some time. Similarly, there were variations in the symptoms as well as the degree of discomfort, and this was seen to be a limitation of this study.

3. The decision to utilize a random sample as the control group meant that an unknown number of persons in this group could possibly have had IC or, even more likely, some other less severe chronic disease. Error in this case, however falls on the side of conservatism when comparing test scores between the Random Control and the IC groups.

Data Analysis

A. Statistical Analysis

Data were analyzed utilizing the specialized Statistical Package for the Social Sciences (SPSS-X). The five research instruments used in this study generated twenty-seven (27) dependent variables for comparison of means. The three groups did not have equivalency in mean age. Therefore, age was noted as a covariate, and a multivariate analysis of covariance (MANCOVA) was performed. Shavelson (1988) and Porter and Raudenbush (1987) recommend the use of analysis of covariance in psychological research to ascertain whether observed differences between means are the result of error variance, chance or systematic differences between the various populations studied.

The Pillais-Bartlett Trace statistical test was employed to determine the significance of the multivariate F for the multivariate analysis of covariance (MANCOVA). Observed and adjusted means were calculated for all dependent variables. Scheffe Post-Hoc comparisons were calculated when significance was noted. While the Scheffe test is equivalent to that used in the ANOVA, statistics are adjusted for the covariate and the error term addresses sampling differences among the groups on the covariate (Shavelson, 1988; Stevens, 1986). Statistically significant results were noted on a number of variables, and are discussed in Chapter 4.

Researchers in applied statistics point to the importance of exploring data for interesting patterns or trends, as a stimulus for further research or theory development (Tukey, 1977; Good, 1983; Maguire, 1986). With this in mind, Z-scores on the adjusted means, were calculated on each variable for the three groups. This linear transformation of data, indicates relative standing, and permits presentation of all variables simultaneously.

While not all variables were statistically significant, the Z-scores point to trends which may assist in understanding more fully the populations studied. The graphical representation of Z-scores are presented two groups at a time, as follows: Random Control group and Interstitial cystitis group and the Random Control group and Urinary tract infection group (in Chapter 4). Exhibiting the data in this manner served to illustrate the overall complexion of the IC, Urinary Tract Infection and Random Control groups.

For each significant analysis of covariance (ANCOVA's), mean scores were compared at the .05, and .10 levels of significance using the Scheffe procedure. It will be noted that comparability at the .10 level was included for two reasons. First, the Scheffe test, according to Ferguson (1981) and Norusis (1983), is conservative and therefore leads to fewer significant results (Type II error) than do other tests. Second, the study was exploratory in nature and within this perspective a less stringent level of significance was considered appropriate.

Analysis of Covariance

As age was considered a possible covariate, two procedures were followed in order to determine whether an analysis of covariance was appropriate (Stevens, 1986). Firstly, a significant relationship between dependent variables and the covariate was verified. Table 1 indicates that a significant linear relationship exists between the dependent variables and age.

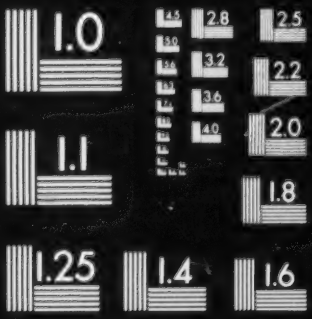
TABLE 1. LINEAR RELATIONSHIP BETWEEN DEPENDENT VARIABLES AND AGE

Name	Value	Approx. F	Hypoth. DF	Error DF	Sig. of F
Pillais	.47752	4.04245	26.00	115.00	.000

As this initial check was satisfied, homogeneity of regression lines was then examined in response to the second stipulation for the use of covariance (Stevens, 1986). A check for homogeneity of the regression hyperplanes is displayed in Table 2.

TABLE 2. TESTING FOR HOMOGENEITY OF REGRESSION HYPERPLANES.

Name	Value	Approx. F	Hypoth. DF	Error DF	Sig. of F
Pillais	.40504	1.11349	52.00	228.00	.293



MICROCOPY RESOLUTION TEST CHART
NATIONAL BUREAU OF STANDARDS
STANDARD REFERENCE MATERIAL 1010a
(ANSI and ISO TEST CHART No. 2)

The effect in this instance was not significant, which means the umption is tenable and an analysis of covariance is appropriate. s is one of the few occasions where significance is undesirable evens, 1986).

Table 2, confirms that the regression hyperplanes are ogeneous for the IC, Urinary Tract Infection and Random Control ups. Subsequently, a multivariate analysis of covariance was nd to be fitting in this instance, and was therefore performed h the assumption of homogeneity.

B. Ancillary Information

A Questionnaire

In addition to the general battery of tests administered to all ups, interstitial cystitis patients also answered an extensive dical and family history inventory (Appendix B).

Demographic data including age, time since diagnosis of terstitial cystitis, number of physicians visited before obtaining correct diagnosis, year of diagnosis, allergies, history of rgeries, family history of bladder problems or disease, amount of dication taken to relieve symptoms of interstitial cystitis, and evious trauma to the bladder prior to onset of interstitial stitis were obtained.

This ancillary information was coded numerically so that it ld be reported in percentages (see Chapter 4). At the time of ing this information, missing data on the ICA questionnaire (see endix B), were noted. This may have been due to an attenuated inistration time, difficulties in recalling psycho-physiological ormation, or having a limited awareness of the mind-body nection in the disease process. Percentages of IC patients ponding to various questions were calculated and are presented in pter 4.

erview Data

A combined questionnaire and interview format is favored by ial science researchers, as it is conducive to the expansion of entific knowledge (Agnew & Pyke, 1987). In this study interview were considered strictly from an exploratory perspective, and ved a dual purpose. Firstly, it provided an opportunity to ten to IC patients as they shared their life experiences as well their encounter with this disease. While these personal accounts subjective and retrospective, they contribute to a presently ited interstitial cystitis knowledge base. Secondly, this orial was seen as a means of fostering an understanding of the cerns and needs of the IC patient as an individual, and in a more oral sense, as a specific patient population requiring medical atment and care.

Responses to interview questions were coded and computed as
entages, where possible. As with the medical and family history
tionnaire, coded interview material constituted part of the
ntitative documentation.

Results

The results of this study are presented in two main sections. The first is concerned specifically with the testing of research questions and corresponds in sequence to the process followed in the data analysis. The second section is comprised of a more informal report outlining both group and individual responses to the ICA questionnaire and the structured interviews.

In summary, the intent of the research questions was to explore a number of psychosocial and behavioral health characteristics as they may pertain to interstitial cystitis patients. This was carried out through the administration of a battery of inventories.

The characteristics of anxiety, irrational ideas, internal-external locus of control, health locus of control, as well as several behavioral health attitudes were examined among females within three separate research groups. While quantitative results were the prime focus of this exploratory investigation, qualitative material obtained from interviews with IC patients has also been used where appropriate to amplify and illustrate the principal findings.

A. Analysis of Research Variables

The analysis of the relationship among the above variables volved several statistical procedures. Scatterplots (box and iskers) were initially produced in order to view the dispersion thin groups across the various variables. This "data snooping" ovided a means of assessing potential difficulties caused by tlyers or exceptional data points, and illuminated the need for a mber of cautionary measures adopted in the final analyses.

As a result of this preliminary analysis it was determined that series of statistical analyses needed to be employed to estimate e significance of results in relation to the stated research estions. Firstly, total mean scores across all groups for all riables were compared using the MANCOVA (Pillais-Bartlett Trace) rocedure. In this analysis "age" was used as the covariate.

Following this, adjusted Z-scores were calculated for each group cross all measures. This assisted in obtaining a "feel" for the ata, before more sophisticated and specific analyses were under aken.

As a means of assessing differences among groups, univariate -tests were conducted. This statistical procedure was considered ore conservative than separate ANOVA procedures, and indicated hose variables which needed further analysis.

Finally, post hoc Scheffe comparisons were completed as a means f estimating between group differences on variables where nivariate F-tests showed significant differences among groups.

hese results then, are reported in the following section according o the appropriate Hypothesis.

ultivariate Analysis of Covariance

A multivariate analysis of covariance was employed to test the ain effects across all variables (see Table 3). Results of the illais-Bartlett Trace Test indicated the significance of F as being reater than .001. This then confirmed that statistical differences ere observed among groups across all variables taken together as a hole.

TABLE 3. MULTIVARIATE TEST OF COVARIANCE

Name	Value	Approx. F	Hypoth. DF	Error DF	Sig. of F
Pillais	.60264	1.92414	52.00	232.00	.001

omparison of Z-Scores

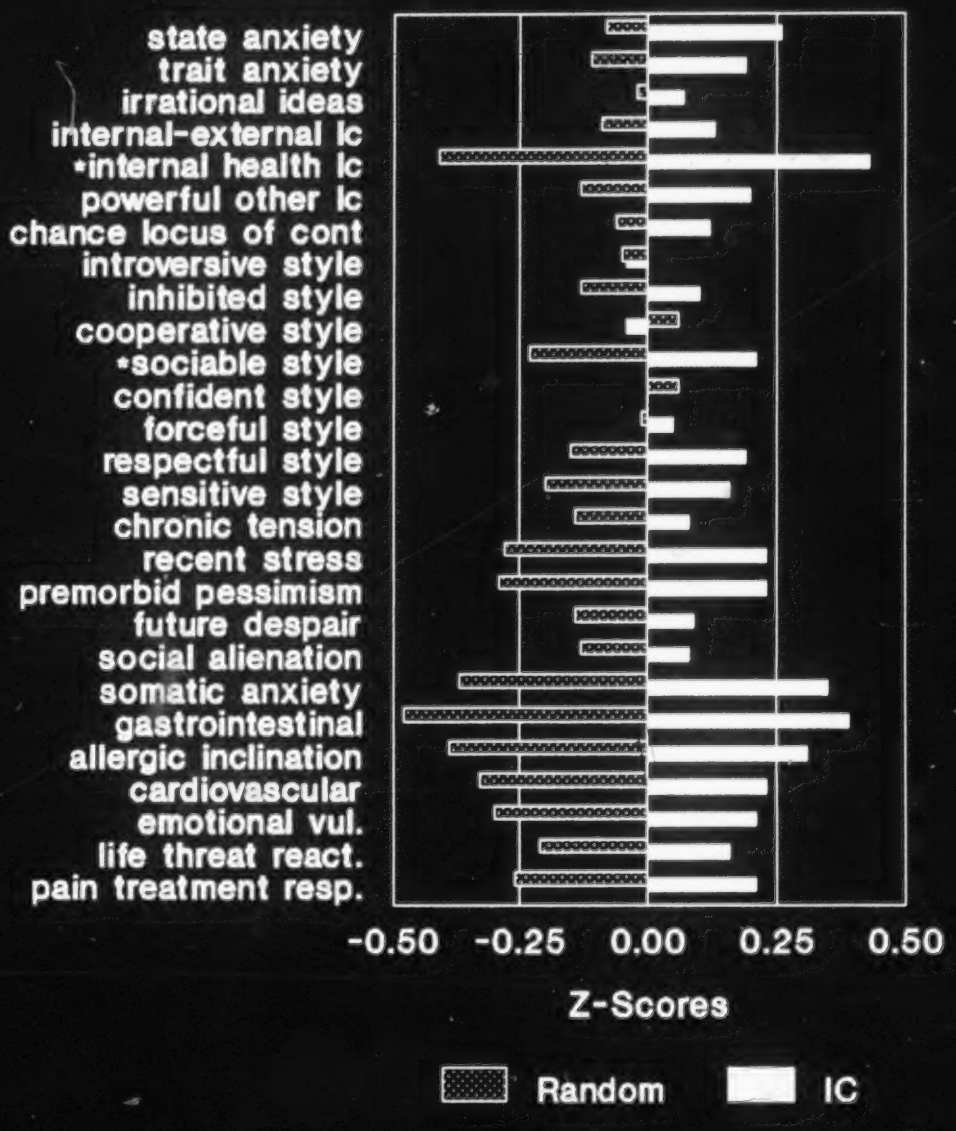
To provide a more understandable framework for the presentation nd discussion of results, adjusted Z-scores on observed means were alculated and reported in Table 4. They were then graphically epicted (Figure 2 and 3), in order to illustrate the overall ifferences between the IC group and both the Urinary Tract nfection (cystitis) and Random Control groups.

TABLE 4. ADJUSTED Z-SCORES ON ALL VARIABLES FOR THE IC, URINARY TRACT INFECTION AND RANDOM CONTROL GROUPS

Variable	IC	UTI	RANDOM
State-Trait Anxiety			
State Anxiety	.26	-.24	-.08
Trait Anxiety	.19	-.12	-.11
Adult Irrational Ideas			
Irrational Ideas	.07	-.07	-.02
Rotter I-E Scale			
Internal-External LOC	.13	-.06	-.09
Multidimensional Health Locus of Control			
Internal Health LOC	.43	-.14	-.41
Powerful Other LOC	.20	-.16	-.13
Chance Locus of Control	.12	-.08	-.06
Millon Behavioral Health Inventory			
Introversive Style	-.04	.06	-.05
Inhibited Style	.10	.02	-.13
Cooperative Style	-.04	-.03	.06
Sociable Style	.21	-.04	-.23
Confident Style	.00	-.04	-.06
Forceful Style	.05	-.03	-.01
Respectful Style	.19	-.12	-.15
Sensitive Style	.16	.02	-.20
Chronic Tension	.08	.07	-.14
Recent Stress	.23	.02	-.28
Premorbid Pessimism	.23	.01	-.29
Future Despair	.09	.03	-.14
Social Alienation	.08	.04	-.13
Somatic Anxiety	.35	-.07	-.37
Gastro Susceptibility	.39	-.02	-.48
Allergic Inclination	.31	.00	-.39
Cardiovascular Tendency	.23	.05	-.33
Emotional Vulnerability	.21	.04	-.30
Life Threat Reaction	.16	.02	-.21
Pain Treatment Response	.21	.01	-.26

IC and Random Groups

Comparison of Z-Scores

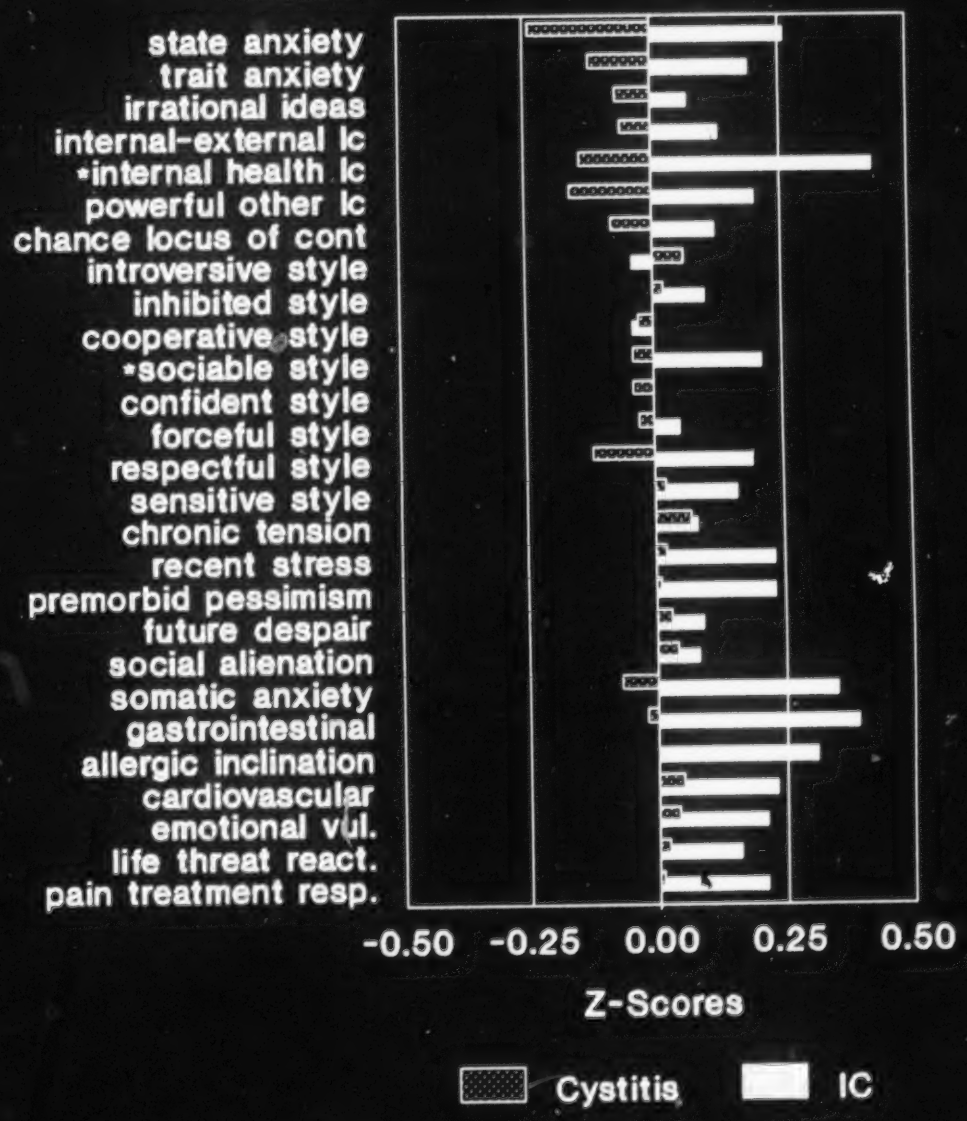


• *Value Reversed*

Figure 2

IC and Cystitis Groups

Comparison of Z-Scores



Value Reversed

Figure 3

While these graphs are not bound to statistically significant differences, they do present the reader with a more visual representation of the overall effects across the total number of variables, as reported by the highly significant Pillais Test in Table 3. The intention then, is to demonstrate the observed differences between the IC group and the Urinary Tract Infection and Random Control groups as a whole, and not to analyze individual scores on each variable. Such analysis must only be considered in the context of the more rigorous post hoc Scheffe comparisons, which are reported later in this chapter.

It is clear from studying Figure 2 and Figure 3 that the IC group stands out clearly and separately from the Urinary Tract Infection and Random Control groups on most of the twenty-seven (27) variables studied. The observed differences which are significant, are of course important and central to the study, and will be reported in the following section.

Univariate F-tests and Post Hoc Scheffe Comparisons

Univariate F-tests were then performed on dependent variables, as shown in Table 5. Here it can be seen that the significance of F was found to be greater than .05 among groups on several variables including: state anxiety, internal health locus of control, recent stress, premorbid pessimism, somatic anxiety, emotional vulnerability, gastrointestinal susceptibility, allergic inclination and cardiovascular tendency.

TABLE 5. UNIVARIATE F-TESTS AMONG GROUPS ON ALL VARIABLES, WITH (2, 140) DEGREES OF FREEDOM

Variable	Hypoth. MS	Error MS	Value F	Sig of F
State-Trait Anxiety				
State Anxiety	**401.364**	**133.135**	**3.01472**	**.05***
Trait Anxiety	192.208	129.239	1.48722	.23
Adult Irrational Ideas				
Irrational Ideas	391.209	403.025	.97068	.38
Rotter I-E Scale				
Internal-External LOC	9.395	14.994	.62654	.53
Multidimensional Health Locus of Control				
Internal Health LOC	**902.221**	**93.087**	**9.69228**	**.0001***
Powerful Other LOC	228.067	100.027	2.28006	.11
Chance Locus of Control	57.527	99.447	.57846	.56
Millon Behavioral Health Inventory				
Introversive Style	2.778	15.823	.17557	.84
Inhibited Style	32.301	48.777	.66221	.52
Cooperative Style	2.046	16.892	.12115	.89
Sociable Style	104.187	42.561	2.44793	.09
Confident Style	3.187	29.278	.10886	.90
Forceful Style	1.814	20.578	.08817	.92
Respectful Style	29.569	16.599	1.78140	.17
Sensitive Style	83.817	52.442	1.59828	.21
Chronic Tension	16.561	22.600	.73280	.48
Recent Stress	**36.105**	**10.651**	**3.38987**	**.03***
Premorbid Pessimism	**183.594**	**55.000**	**3.33802**	**.03***
Future Despair	29.847	45.389	.65759	.52
Social Alienation	18.698	32.999	.56662	.56
Somatic Anxiety	**216.094**	**32.140**	**6.72356**	**.002***
Gastro Susceptibility	**171.638**	**17.084**	**10.04658**	**.0001***
Allergic Inclination	**163.052**	**26.409**	**6.17412**	**.003***
Cardiovascular Tendency	**105.789**	**27.423**	**3.85761**	**.02***
Emotional Vulnerability	**15.684**	**4.822**	**3.25253**	**.04***
Life Threat Reaction	56.648	35.930	1.57664	.21
Pain Treatment Response	93.605	34.645	2.70186	.07

* denotes differences among groups at the 0.05 level

Hypothesis 1

Female interstitial cystitis patients will score higher on measures of anxiety than will persons in a female Urinary Tract Infection group or a Random Control group.

Results: State-Trait Anxiety

On Spielberger's (1983) State-Trait Anxiety (STAI) Scale, the obtained F value indicates a significant difference among groups on **state anxiety** (see Table 5). No differences were observed on the variable **trait anxiety**.

As the obtained F value on **state anxiety** (see Table 5) indicate significant difference among groups, a post hoc Scheffe comparison (Table 6) was performed and revealed that these differences could b found between the interstitial cystitis and urinary tract groups. However, no significant differences were noted on **trait anxiety**.

TABLE 6. SCHEFFE COMPARISON ON STATE ANXIETY FOR IC, URINARY TRACT INFECTION AND RANDOM GROUPS

GROUPS	ADJUSTED MEAN	IC	UTI	RANDOM
1 IC	40.98		*	
2 UTI	35.25	*		
3 RANDOM	37.07			

* denotes pairs of groups significantly different at the 0.1 leve

Conclusion: State-Trait Anxiety

Hypothesis 1 was only partially supported on the basis of this analysis. Female IC patients as a group scored higher on state anxiety than the Urinary Tract Infection group, but not significantly higher than the Random Control group. Hypothesis 1 was not supported at all for the variable trait anxiety.

Hypothesis 2

Female interstitial cystitis patients will score higher on a measure of irrational ideas than will persons in a female Urinary Tract Infection group or a Random Control group.

Results: Irrational Ideas

The F value obtained on a measure of irrational ideas (Adult Irrational Ideas Inventory (Davies & Zingle, 1970), indicated no significant differences among the Interstitial Cystitis, Urinary Tract Infection (cystitis) and Random Control groups (see Table

Post Hoc Scheffe comparisons on irrational thinking were not performed as no significant differences were observed on univari F-tests.

Conclusion: Irrational Ideas

Hypothesis 2 was rejected on the basis of these results.

Results: Locus of Control

The F value obtained on the Rotter Internal-External Locus of
rol Inventory (Rotter, 1966) indicated no significant
erences among the IC, Urinary Tract Infection and Random Contro
os (see Table 5).

Post Hoc Scheffe comparisons on **internal-external locus of**
rol were not performed as no significant differences were
rved on univariate F-tests.

The Multidimensional Health Locus of Control Scales, which
eate three different categories: **internal health** locus of
rol, **powerful other** locus of control and **chance** locus of
rol, were also utilized to measure locus of control. Univariat
ts (Table 5) revealed significant differences among groups on
rnal **health** locus of control, with no differences on either
rful **other** or **chance** locus of control.

Scheffe comparisons on **internal health** locus of control reveale
significant differences existed between the IC group and both
rinary Tract Infection and the Random Control groups. These
ts, along with adjusted means are presented in Table 7.

LE 7. SCHEFFE COMPARISON ON INTERNAL HEALTH LOCUS OF CONTROL FOR IC, URINARY TRACT INFECTION AND RANDOM GROUPS

GROUPS		ADJUSTED MEAN	IC	UTI	RANDOM
1	IC	45.49		+	+
2	UTI	51.28	+		
3	RANDOM	54.01	+		

otes pairs of groups significantly different at the 0.05 level

should be noted that higher mean scores reflect more
ality, while lower scores indicate a more external locus of
l related to health attitudes and behaviors. Thus, the IC
was found to be more external than either the cystitis or the
group on this measure.

onclusion: Locus of Control

ypothesis 3 was rejected on three out of the four Locus of
l measures.

Hypothesis 4

emals interstitial cystitis patients will score differently on in measures of behavioral health attitudes and coping styles will persons in a Urinary Tract Infection and a Random Control .

esults: Millon Behavioral Health Inventory

he Millon Behavioral Health Inventory, is comprised of twenty

ub-scales which can be grouped under four broad categories (Millon, reen and Meagher, 1982): basic coping styles, psychogenic attitude cales, psychosomatic correlate scales, and prognostic indices cales. Using univariate F-tests (see Table 5), non-significant ifferences were observed on thirteen sub-scales. However, ignificant results were noted on seven sub-scales as follows:

a. **Recent Stress**

b. **Premorbid Pessimism**

c. **Somatic Anxiety**

d. **GastroIntestinal Susceptibility**

e. **Allergic Inclination**

f. **Cardiovascular Tendency**

g. **Emotional Vulnerability**

1. **Basic Coping Styles**

Within the basic coping style category, no single sub-scale core was found to be significant following the calculation of nivariate F-tests.

2. **Psychogenic Attitude Scales**

Univariate F-tests revealed that three scales within the sychogenic attitude category had significant differences (see able 5) among groups. Comparisons show that differences were found mong the Interstitial Cystitis, Urinary Tract Infection and Random ontrol groups on measures of **recent stress, premorbid pessimism** and **omatic anxiety.**

Table 8 displays differences between groups, along with the adjusted means for the recent stress scale. These post-hoc Scheffe comparisons clarify that the IC group is significantly different from the Random Control group.

Higher scores related to recent stress are purported to reflect personal feelings and perceptions regarding psychological stress, which may increase psychosomatic susceptibility or exacerbate existing health concerns (Millon, Green and Meagher, 1982).

TABLE 8. SCHEFFE COMPARISON ON RECENT STRESS FOR IC, URINARY TRACT INFECTION AND RANDOM GROUPS

GROUPS	ADJUSTED MEAN	IC	UTI	RANDOM
1 IC	7.138			+
2 UTI	6.428			
3 RANDOM	5.394	+		

+ denotes pairs of groups significantly different at the 0.05 level

The dispositional attitude of helplessness-hopelessness is addressed through the premorbid pessimism scale. A sense of pessimism and gloom as it pertains to health matters may cause a loss of hope in life generally (Millon, Green and Meagher, 1982). This attitude can have an impact upon the daily life and relationships of individuals. Univariate F-tests (see Table 5) identified significant differences among groups on premorbid pessimism.

Scheffe comparisons on premorbid pessimism show that these ifferences can be found between the IC and the Random Control roups (Table 9).

TABLE 9. SCHEFFE COMPARISON ON PREMORBID PESSIMISM FOR IC, URINARY TRACT INFECTION AND RANDOM GROUPS

GROUPS	ADJUSTED MEAN	IC	UTI	RANDOM
1 IC	11.49			+
2 UTI	9.87			
3 RANDOM	7.55	+		

+ denotes pairs of groups significantly different at the 0.05 level

A significant difference was also observed on the somatic axiety scale of the Millon Behavioral Health Inventory (see able 5). Higher scores on this scale indicate a greater reoccupation and fear regarding bodily functions. Concerns which enter around one's physical state, may result in hypochondria or inor illness (Millon, Green & Meagher, 1982).

The Scheffe comparison (Table 10) shows that significant ifferences exist between the IC group and both the Urinary Tract nfection and the Random Control groups.

TABLE 10. SCHEFFE COMPARISON ON SOMATIC ANXIETY FOR IC, URINARY TRACT INFECTION AND RANDOM GROUPS

GROUPS	ADJUSTED MEAN	IC	UTI	RANDOM
1 IC	13.08		*	+
2 UTI	10.57	*		
3 RANDOM	8.83	+		

* denotes pairs of groups significantly different at the .10 level
+ denotes pairs of groups significantly different at the .05 level

3. **Psychosomatic Correlates Scales**

The psychosomatic correlate scales of the Millon Behavioral Health Inventory are generally used with patients diagnosed with specific disease syndromes. Here, the interstitial cystitis patients scored significantly higher on all measures, including **allergic inclination, gastrointestinal susceptibility and cardiovascular tendency.** Higher scores on these measures often point to the impact of emotional factors and stress in precipitating or contributing to the disease process.

The **gastrointestinal susceptibility** scale was found to be particularly sensitive to differences among groups, as can be seen in Table 5. Using a post-hoc Scheffe comparison, differences were established between the IC group and both the Urinary Tract Infection and the Random Control groups. In addition, differences were also observed between the Urinary Tract Infection and the Random Control groups (Table 11).

TABLE 11. SCHEFFE COMPARISON ON GASTROINTESTINAL SUSCEPTIBILITY FOR IC, URINARY TRACT INFECTION AND RANDOM GROUPS

GROUPS		ADJUSTED MEAN	IC	UTI	RANDOM
1	IC	10.00		*	+
2	UTI	8.19	*		*
3	RANDOM	6.19	+	*	

* denotes pairs of groups significantly different at the .10 level
+ denotes pairs of groups significantly different at the .05 level

Results of the univariate F-test on **allergic inclination** revealed significant differences as shown in Table 5. Once again, post-hoc Scheffe comparisons indicate that differences exist between the IC and the Random Control groups (Table 12).

According to Millon, Green and Meagher (1982), higher scorers on **allergic inclination** often experience emotional or social factors as precipitants to the disease process.

TABLE 12. SCHEFFE COMPARISON ON ALLERGIC INCLINATION FOR IC, URINARY TRACT INFECTION AND RANDOM GROUPS

GROUPS		ADJUSTED MEAN	IC	UTI	RANDOM
1	IC	12.37			+
2	UTI	10.75			
3	RANDOM	8.66	+		

+ denotes pairs of groups significantly different at the 0.05 level

Post-hoc Scheffe comparisons on **cardiovascular tendency** revealed that the IC group was significantly different from the Random Control group. Table 13 presents the differences between groups, along with adjusted mean scores for **cardiovascular tendency**.

TABLE 13. SCHEFFE COMPARISON ON CARDIOVASCULAR TENDENCY FOR IC, URINARY TRACT INFECTION AND RANDOM GROUPS

GROUPS	ADJUSTED MEAN	IC	UTI	RANDOM
1 IC	14.48			+
2 UTI	13.55			
3 RANDOM	11.53	+		

+ denotes pairs of groups significantly different at the α0.05 level

4. Prognostic Categories

Of the three sub-scales comprising the prognostic category, only **emotional vulnerability** was found to be significantly different among groups. Post-hoc Scheffe comparisons identify these differences as occurring between the IC and the Random Control groups (Table 14).

TABLE 14. SCHEFFE COMPARISON ON EMOTIONAL VULNERABILITY FOR IC, URINARY TRACT INFECTION AND RANDOM GROUPS

GROUPS		ADJUSTED MEAN	IC	UTI	RANDOM
1	IC	2.167			+
2	UTI	1.774			
3	RANDOM	1.026	+		

+ denotes pairs of groups significantly different at the 0.05 l

Millon, Green and Meagher (1982) suggests that **emotional vulnerability** refers to a more negative expectation about medica treatment, and is often the result of lived experience. Higher scores suggest that, as a group, interstitial cystitis patients could be more susceptible to depression when having to confront chronic or progressive illness.

Conclusions: Millon Behavioral Health Inventory

On the basis of this analysis it can be concluded that femal interstitial cystitis patients as a group, scored differently th did the Urinary Tract Infection group and Random Control group o two measures of behavioral health attitudes. More specifically, Hypothesis 4 was fully upheld on the subscales of the Millon Behavioral Health Inventory known as **somatic anxiety**, and **gastrointestinal susceptibility**. In addition, it was partially upheld on five of the twenty sub-scales, including **recent stress premorbid pessimism, allergic inclination, cardiovascular tender** and **emotional vulnerability**.

CONCLUSIONS

Hypothesis 1

Female interstitial cystitis patients will score higher on measures of anxiety than will persons in a female Urinary Tract Infection group or a Random Control group.

In summary, the preceding findings suggest the following conclusions:

State Anxiety - partially supported

Trait Anxiety - rejected

Hypothesis 2

Female interstitial cystitis patients will score higher on measures of irrational thinking than will persons in a female Urinary Tract Infection group or a Random Control group.

In summary, the preceding findings suggest the following conclusions:

Adult Irrational Ideas - rejected

Hypothesis 3

Female interstitial cystitis patients will score higher on measures of external locus of control than will persons in a fema Urinary Tract Infection group or a Random Control group.

In summary, the preceding findings suggest the following conclusions:

Internal-External Locus of Control	-	rejected
Internal Health Locus of Control	-	supported
Powerful Other Locus of Control	-	rejected
Chance Locus of Control	-	rejected

Hypothesis 4

Female interstitial cystitis patients will score differently certain measures of behavioral health attitudes and coping style than will persons in a Urinary Tract Infection and a Random Cont group.

In summary, the preceding findings suggest the following conclusions:

Basic Coping Styles:

Introversive Coping Style	-	rejected
Inhibited Coping Style	-	rejected
Cooperative Coping Style	-	rejected
Sociable Coping Style	-	rejected

Confident Coping Style	-	rejected
Forceful Coping Style	-	rejected
Respectful Coping Style	-	rejected
Sensitive Coping Style	-	rejected
Psychogenic Attitude Scales:		
Chronic Tension	-	rejected
Recent Stress	-	partially supported
Premorbid Pessimism	-	partially supported
Future Despair	-	rejected
Social Alienation	-	rejected
Somatic Anxiety	-	supported
Psychosomatic Correlate Scales:		
Allergic Inclination	-	partially supported
Gastrointestinal Susceptibility	-	supported
Cardiovascular Tendency	-	partially supported
Prognostic Indices Scales:		
Pain Treatment Responsivity	-	rejected
Life Treat Reactivity	-	rejected
Emotional Vulnerability	-	partially supported

Interstitial Cystitis Association

Questionnaire and Interviews

The data which follows are seen to be ancillary information provided by interstitial cystitis patients on the ICA Questionnaire or during an indepth interview. The structured interview questions found in Appendix E, served as a framework in categorizing the subject headings which are presented below.

While the material provided by IC patients during interviews is subjective in nature, it is provided for the reader as a means of furthering an understanding of the lived experiences of these patients. This information is strictly exploratory, however it may provide insight into this disease process as well as to stimulate further research.

Subjective Inconvenience to Daily Living

The symptoms of IC appear to cause subjective inconvenience in daily living. Sixty (60) percent of those responding described the pain as a constant burning, debilitating or at times unbearable. Said one patient,

> My bladder is like a house on fire, but at least a house fire can be put out - this can't be put out, it can only be controlled to a point. There's pain there like an oil well out of control, smoldering all the time, then it flares up. I feel like something has got to give - this bladder can't burn on forever. When it's so bad, I feel like it's doing so much damage to me. I feel like dancing up and down, screaming for help. I think the only thing that would help me is a sedative to put me asleep and out of my misery.

Another IC patient expressed it this way,

> It's the worst pain I've ever had. I've had hip surgery and really bad pain - this is worse than childbirth. I don't feel like I have control over myself. I'm always planning around the bathroom. I am an active person and it was devastating- feeling sick and it running my life.

Words Used to Describe Illness

A number of researchers have emphasized the importance of listening to the words, or "verbal markers" as well as the speech patterns patient's use in talking about their illness (Gottschalk Gleser, 1969; Graham, Lundy, & Benjamin, 1962; Jung, 1964; Kimbal 1969, 1982; Pearsall, 1987; Siegel, 1986, 1989).

Siegel (1989) writes, "there is always more to disease than t mere physical diagnosis. The people it is easiest to help are th one's who describe their experience of the disease, because as th talk about their illness, the words always apply to the life tha gave rise to it" (p. 51).

The words used by interstitial cystitis patients, are also s to be not only descriptive of a disease process, but also as a reflection of what is happening in her life. Listening to the w a patient uses to describe her/his illness, can provide invaluab information in treating the person with the disease. One such example taken from an in-depth interview is presented:

> My IC feels: hot -like a hot poker, shooting up. It feels like a hot spot on my side. A burn on the inside and kind of sore. There's a real sore core down in the middle. The core feels like it shoots up.. it hurts so bad - the pain is bad and it wakes me up. It comes on so quick and

unexpected. Sometimes it attacks me when
when we are having company or visiting a
pacing. I feel better when I'm walking
can't sit or stand or stay in bed long.

This interstitial cystitis patient has n
knife-point (she could feel the knife poi
ldhood. The rape was never discussed unt
sulted a psychiatrist. At that time, the
her that "she couldn't be too traumatized
".

It is intriguing to look at the words se
erstitial cystitis: "hot poker", "core do
ts so bad", "sometimes it attacks me"....
unexpected". These descriptors may in pa
cumstance that has not achieved resolutio
e adjunctive therapy may be in order.

Pain and Interstitial Cystitis

Thirty-nine (39) percent of IC patients
stion regarding how often they experience
almost continual. Fifty nine (59) percen
dy describe their pain as either a consta
ilitating pain, or at times unbearable.
ptoms, namely the frequency, urgency and

n I'm driving or
nd it puts me to
back and forth. I

ever resolved her rape
nt in her side) during
ll recently, when she
psychiatrist indicated
if she still enjoyed

lected to describe the
wn the middle", "it
'it comes on so quick
art reflect a life
n, and implications for

esponding to a
pain, report that it
of IC patients in this
t burning, a
These dis-quietening
burning often result in

venty-one (71) percent of IC patients responding to questions
ation of pain (ICA Questionnaire), indicated that they
ence bladder pain; fifty (50) percent stated that they have
n urination; fifty-seven (57) percent report abdominal pain;
irty-eight (38) percent report urethral pain.

e following expresses the sentiments of an IC patient in
on to the physical pain:

> When I'm going through a bad bout of IC, this is the
> ly thing on my mind - trying to get rid of the pain. I'm
> t aware of any other part of my body, just the bladder,
> d the whole area seems to be affected. I have no control
> otionally and physically.

pression

fty-four (54) percent of IC patients responding to a
on on depression, indicated that they have felt despondent
feelings of gloom.

is sense of hopelessness or melancholy was expressed by one
ient this way:

> At times I didn't care what happened, I felt like
> mmitting suicide. The doctor told me he couldn't do
> ything more. The next step was to remove my bladder.

nother IC patient expressed feelings of depression in this

> I feel depressed thinking about things, like having an
> nhealthy baby. I feel that I'm bad, I'm dirty, all these
> nings people have said made me feel bad..for instance, I

an allergy, but My Mom jokingly says when I'm sick (with the allergy or the IC), that it is the badness coming out in me. She says it as a joke, but it makes me wonder - have I been bad and now I'm paying for it?

Body Tension

On a question pertaining to where IC patients hold their sion, of those responding, sixty-four (64) percent have an reness of containing tension within their upper body (jaw, and shoulders). On a question more specifically addressing tension, forty-five (45) percent of IC patients answering question indicated they routinely clench their jaws.

In the words of a twenty-eight year old mother of three:

I hold tension in my mouth and teeth. From clenching my jaws I've gone through two pairs of dentures - all the time I'm clenching. If I'm angry or tense, I tend to bite down and clench. I often don't say what I really want to say. I used to let everything eat away at me and let other people bother me.

her IC patient reflected:

I clench my teeth, and I'm aware of clenching my jaw. I'm a person of tension. I run around a lot and do a lot of things for everyone. Tension, is a natural tension from trying to please everyone. The kids are always on my mind with what they do - There is worry and tension about them.

Unexpressed anger

With respect to the expression of anger, fifty-nine (59) percent

dicated they typically do not release or express their anger as a

ter of course. The sentiments of several IC patients are given

illustrate how many people within this group feel:

I have always tried to cover things up. I don't know why, I stuff it down inside somewhere.

I swallow my feelings. Somewhere inside there's a lot of feelings. I wanted to cry but I can't, so I shut it down. Lots of things in my life have been stressful. I feel the tears come when I talk of my Mom's death.

I had to handle it (my feelings and anger) myself. If things are bad, you don't talk about it and it will go away. One incident I remember that was never talked about and it should have been!- I will never forget it!.

Perfectionism

Fifty-nine percent of IC patients participating in the

terview, indicated that they perceive themselves to be

rfectionists, or have perfectionist tendencies in some area of

eir lives. In the words of several IC patients:

I have high expectations for myself, I am an achiever, I like to succeed at what I do and work at - I like things to be done well, I am perfectionistic.

My friends and kids see me as meticulous- I think I am a perfectionist. When my Mom died, I arrived at the hospital and realized I was dressed up including lipstick and earrings, - but I did it automatically.

I am a meticulous housekeeper- I get the gears for it! I like it (the house) tidy - things in place. The family, my kids tease me about how neat I am. I straighten up their places! Others say my home looks like a show place, it's so clean and tidy.

Urological Problems During Childhood

The ICA Questionnaire addressed urological problems during ildhood, and of those IC patients responding to these questions, enty-three (23) percent indicated they had been bed wetters during eir formative years, and fifty-seven (57) percent reported having en told to "hold their urine" or did hold their urine even though ey felt the need to go.

Several IC patients revealed rather traumatic incidents related bedwetting during the years of childhood. In the words of a ddle aged woman:

> I went to live in an orphanage at the age of six. My three brothers went to one together and I went to one by myself. The nuns raised me until I was thirteen. I used to wet the bed. The nuns would make me stand with the wet (urinated) sheets over my head while the other girls dressed. I had to stand in the middle of the room, and they (the nuns) would throw the "pissy" sheets on my head. I was humiliated. I kept my head down, but everyone knew and they called me names. It affected me badly. At night if I wet the bed, I would take the sheets down to the bathroom and wash it in the toilet, and let it dry over the radiator, so I wouldn't be found out and I would be liked.

ther woman expressed it this way:

> Sometimes I wet my bed, when I was eight or nine, and my Dad would strap me with a belt. He would pull the blankets back and strap me if it (the bed) was wet. I try to forget these things, to get over it, but I can't talk about it without crying. There are feelings of anger and humiliation. Anger at my Dad because I couldn't help wetting myself. I kept the anger inside and tried to forget it. But I guess I didn't forget it.

Sexual Functioning

Of those interstitial cystitis patients responding to a question garding whether IC has affected their sexual functioning, forty-e (41) percent indicated the affirmative.

> When the IC is really bad, it affects it (sexual intercourse) - because I get increased frequency with sex. I want my partner to be very careful where he touches me. I think too, of what sex will do to the state of the IC after sex- I have to be careful..it's always in the back of my mind. I have a ritual for after sex, drinking lots of water etc...

> IC has affected our sexual relationship. Always having to go to the bathroom - your partner has to see the humor in having to go to the bathroom all the time- surrounding sex.

Traumatic Events in Childhood

Fifty-five (55) percent of those responding to an item in the CA Questionnaire, as well as reports during the interview indicate hat over half the patients participating in this study experienced ome childhood trauma. While this was subjective and retrospective aterial, interstitial cystitis patients acknowledged the impression nd effect the event(s) still carried for them in their lives.

The range of experiences was varied and included: a father's uicide, sexual abuse by a brother, attempted rape, family lcoholism, being lost in a swamp area at age five years, a mother ndergoing thirty-three (33) surgeries, pregnancy and the surrender f the infant for adoption and physical and emotional abuse.

With regard to stress prior to the onset of interstitial

titis, fifty-two (52) percent of those responding to this

stion revealed an awareness of stressful events in their lives

n their symptoms first appeared. The stresses before onset

lude such events as:

- a spouse's open heart surgery
- a heart attack and unhappiness with job pressures
- bladder trauma due to surgery
- husband diagnosed with Amyotrophic Lateral Sclerosis
- death of a daughter
- worries and pressures from a daughter
- husband's prostrate cancer
- three major stressful events occurring one after the other:
  - death of a husband, followed by the death of a grandson (killed while riding his tricycle), followed by the suicide of the grandson's father;
- severe financial troubles
- hysterectomy and multiple kidney and bladder infections
- mother killed, sister injured in a car accident while on th way to visit; and recently surgery to remove her bladder
- married to a sexually abusive partner
- breast cancer
- alcoholic husband
- husband severely beaten and is now a partial quadrapelegic

One woman describes the traumatic events in her life prior to

onset of interstitial cystitis:

I absolutely had traumatic things happen to me several years before the onset of this thing!..You see, my husband died in 1970 and my son in '73, and then just before my husband died - the year before that, my grandson was killed.

There was a bus at the intersection, and the child was getting ready to ride out onto the highway..my grandson saw a car coming and when the car passed he sped onto the highway and there was a car behind it..So as I say, there were three things kind of close.

Mind you I never felt . . . really I know it was bad and it was hard, but you know when you're working you don't have time to think ..at night there was work to do.

I think my problem was that I was keeping myself too busy. I think I subdued my emotions too much. I kept them inside and I also tried to put on a brave front. I'm not one to cry - I couldn't cry..this was not good. It's been like that for a long time.

As a child I cried too much - I cried easily - my feelings were hurt so easily..I was called a 'crybaby' - so I learned not to cry, and that's where that came from. Then I shut my feelings down -they're there - but they don't come out. I didn't really have that real.."Oh God" cry ..I suppose I still keep pushing it back..I knew that you were supposed to cry, and I tried to cry -I could get some tears, but I couldn't get that good sobbing cry, that you need to have. I know I'd feel better if I could just really cry, but I don't go around feeling sad.

I think of my son -I just thought so much of him -he was such a wonderful person. I think of why didn't I do something ..why didn't I see this..I had no forewarning. He got himself into financial difficulties because first of all..there was a down turn in his business and a bit of a recession and he was in some financial difficulties, and of course it was over my head to help pull him out.

Of course there were alternatives - but I don't think he could see them - I don't think he could accept them..and then he was an alcoholic - he would drink..then he would lay off..then he'd drink and all this added up.

He had three little children, and that was their little boy that was killed . . . the day he committed suicide, was the day of his little boy's birthday - and it was also the date my father died.

As I say there was a bit of pain..when it would get painful, you'd go out and see somebody and talk and try to....sometimes I'd try to be so tired at night -you'd go to sleep.

During the interview, IC patients were asked to complete a stem entence. The responses in many instances indicated frustration, esperation and aloneness in contending with the difficult symptoms f this disease. What follows are glimpses of the feelings many IC atients have experienced.

"Sometimes, my interstitial cystitis has been so bad, I've felt ike. . .

slicing the bladder out - take the scissors and cut it out! I don't want to keep thinking about when it's going to bother me next.

cashing in my cookies - ending it all..life is not worth living this way.

lying down and going to sleep - not forever - or I feel like shouting to the world that I need help! - a real sense of desperation.

I have had suicidal thoughts -I feel depressed. I knew I needed counselling because I felt myself ..a vision of hanging from a rope - afraid I might let go (tears).

it was never getting better - just getting worse. I couldn't stand it anymore. I figured it would eventually destroy my life. At work, at home - I was afraid to go anywhere because of it - but I still did.

As indicated at the outset of this section, the foregoing nformation is offered to provide possible avenues of investigation n furthering research of interstitial cystitis. Chronic diseases uch as IC are indeed complex and multifaceted. For this reason, edical and psycho-social researchers must coalesce their efforts to

CHAPTER 5

Discussion

The central purpose of this research was to determine whether female IC patients exhibit more state and trait anxiety, irrational ideas, are more externally controlled and have different health attitudes and behaviors than do a Urinary Tract Infection and a Random Control group.

While the quantitative results stimulate discussion of the profile of female interstitial cystitis patients, characteristic responses shared by women during the semi structured interviews hav also been presented, to illustrate more intimately the personal experience of living with this chronic disease.

The discussion of findings within this study considers both significant and non-significant results, as well as patterns or trends. The graphical representation (Figure 2) in Chapter 4 may b referred to in the discussion of significant results as well as in terms of trends noted particularly with respect to the IC group. Where appropriate, results are discussed under specific headings. In other instances, clarity is best served by discussing findings conjunction with other variables.

State-Trait Anxiety

Spielberger's (1983) State-Trait Anxiety Inventory produced significant results only on state anxiety. Interstitial cystitis patients were significantly different from the Urinary Tract Infection sample, however no group differences were noted between the Random Control group and IC patients.

One possible explanation comes to mind when thinking about th finding. The standard deviation for the IC group was higher indicating greater variation, as participants scored either very high or very low on this scale. This variation in scores may be reflective of differences in the physical condition of individual patients at the point in time when they completed the questionnai It seems highly likely that a patient who at the time of the stud was experiencing some of the symptoms of the disease would score higher.

Interstitial cystitis patients were the highest scorers on st anxiety, and this seems reasonable considering the nature of the condition and the physical and emotional stress which may be crea and felt not only during recurring episodes of IC, but also in anticipation of some future flare-up.

There were no significant differences noted when comparing th three groups on trait anxiety. At the outset of the study, it wa thought that interstitial cystitis patients would have an inherer tendency to this more permanent and enduring type of anxiety. Th however, was not the case. It would appear that IC patients do

experience only state anxiety based on situational occurrences of anxiety and do not exhibit anxiety as a more durable personality characteristic.

Irrational Ideas

No group differences were noted on a measure of adult irrationa thinking (A-I-I, Davies & Zingle, 1970). Female IC patients were not found to be more irrational as defined by a higher score on thi specific measure of irrational thinking. As a group, IC patients are no different than the Random Control or the Urinary Tract Infection group in terms of Ellis' eleven irrational ideas.

During the interviews with IC patients however, it became apparent that perhaps a kind of negative or pessimistic thinking, while not of the irrational idea variety, may be present. An example of this thinking was expressed by a young IC patient this way: "I should be more successful at writing. I don't do enough. I'm pessimistic about the quality of my work, even though I've bee published. I feel I need someone to be with me - to cure the loneliness". Future research with interstitial cystitis patients might examine thinking style or cognitive style in perhaps a more focused or specific way.

Locus of Control

Locus of control was examined from four perspectives within th

Control (I-E), as well as three specific elements of control relate to health: internal (IHLC) health locus of control, powerful other (POLC) health locus of control, and chance (CHLC) health locus of control (Wallston, Wallston & DeVellis, 1978), were utilized. No significant differences were noted on Rotter's measure of Internal-External locus of control. Interstitial cystitis patients as a group were not more externally controlled as was predicted. In terms of this specific measure of generalized expectancies for control, there appears to be no relationship between Internal-External control and women diagnosed with interstitial cystitis.

Interstitial cystitis patients as a group are not more externally controlled in terms of the perception that they are able or unable to control what happens to them in general life situations. As a group, IC patients appear to be no different in their degree of internality-externality when compared with a Random Control or Urinary Tract Infection group.

Multidimensional Health Locus of Control (MHLC)

When control pertains to attitudes or beliefs about health care and treatment, a difference was noted on one scale of the Multidimensional Health Locus of Control (MHLC, Wallston, Wallston & DeVellis, 1978). It may be that the MHLC isolates a subtle difference pertaining to control and expectations about health.

1. **Internal Health Locus of Control (IHLC)**

On the Internal Health Locus of Control (IHLC), a significant difference was noted among groups on this dimension. Interstitial cystitis patients as a group, were more external than either the Urinary Tract Infection or the Random Control groups. Within the sphere of control, it may very well be that IC patients have cultivated health beliefs or attitudes which reflect externality.

Keller (1988) makes the point that individuals who are internal in terms of health locus of control, are "more knowledgeable regarding disease processes and decision making regarding health matters. Conversely, those with lower internal scores have more illness and show less self-directed preventive care" (p. 98).

While the vast majority of IC patients seem to be more externally controlled in terms of health attitudes, it became apparent during the interviews, that several younger patients were beginning to seek out adjunctive resources and strategies which might prove to be of assistance to them in coping with their disease.

A young IC patient commented, that the most important thing sh had learned from the experience of having this illness, was that " don't let it take control of me, I control it!". A young professional woman summed it up this way, "I decided to go on with things and not let this (IC) hold me back. I'm not sure why, I think I got to the point where I didn't trust doctors, medicine didn't work and I wanted to forget all that. I'd had enough! I

ided I had to do it on my own, and so I started to
ks, to meditate and take charge of myself and my h
It may be that over a period of time, the frustra
iety of living with this chronic condition leads s
rch out strategies whereby they feel more in contr
rall health care.

Perhaps too, a younger generation of patients are
t they as individuals can do to take control and h
en's magazines, television talk shows, newspaper a
kshops and a multitude of self help books are read
educate women in the many ways they can assume mor
a result help themselves to a better quality of li
ter health.

Future research might examine the locus of contro
ms of the length of time a patient has had IC, in
ermine whether this factor has a bearing upon inte
ernality of health locus of control.

2. **Powerful Other Health Locus of Control (POLC)**

Age has been noted in the literature as a factor
luences the Powerful Other (POLC) scale (Winefield
the analysis of covariance (age as a covariate),
be significant within the IC group. As indicated
IC population was older than either the Urinary
Random Control groups. For this reason, prior to

read self help

ealth".

tion and

ome patients to

ol of their

more aware of

elp themselves.

rticles,

ily available

e control, and

fe and perhaps

l construct in

order to

rnality or

which

, 1982). Prior

POLC was found

in Chapter 3,

Tract Infection

controlling for

With increasing age then, higher scores on the POLC scale are ical and to be expected (Winefield, 1982). Winefield (1982) also es that Powerful Other has been found to be significantly higher n persons are facing an acute bout of an illness. While some IC ients may have been experiencing a flare-up of their condition at time of completing the questionnaire, the chronic nature of ir condition may possibly explain why no differences were noted the Powerful Other Locus of Control.

3. Chance Health Locus of Control (CHLC)

No differences were noted among groups on the Chance Health cus of control. As Winefield (1982) suggests, CHLC has been found be more of a "state" measure than either the Internal Health cus of Control or the Powerful Other Locus of Control.

During the course of the study, interstitial cystitis patients re surveyed at all stages of the disease process. Some IC tients were recently diagnosed, while others have lived with this ndition for a number of years. The variation and severity in mptoms could also be important factors in consideration of these ndings.

Interview material as well as the quantitative results suggest at further research is needed to delineate differences in health ocus of control with respect to the length of time IC patients have

Millon Behavioral Health Inventory

The Millon Behavioral Health Inventory (MBHI, Millon, Green & Meagher, 1982) is generally interpreted on an individual basis by analyzing patterns or combinations of high and low sub-scale scores particularly on the eight basic coping style scales. Coping style, according to Millon (1969, 1977) and Millon, Green and Meagher (1982) is indicative of more durable personality traits which are typically reflected in interpersonal relationships. These generalized characteristics are also believed to indicate personal functioning both before and subsequent to any medical treatment (Millon, 1982).

Within this study, the MBHI was used as a research instrument to determine whether there were in fact, differences among the groups on the various subscales. While individual profiles may be obtained to analyze high and low scores in a configural pattern, this was not the focus of this research.

Coping Styles

In terms of group differences, no single basic coping style was found to be significant. This would suggest that on the MBHI, there is as much variation or heterogeneity within the IC group, as there is within the Urinary Tract Infection and Random Control groups.

The variation in personality was also evident during the interviews, as some IC patients discussed their shyness or

iscomfort in social situations, and other IC patients indicated a more gregarious or outgoing nature. To illustrate, one younger IC patient shared: "My friends are very social people and I am not that way at all. My friends are smooth and natural. It's no effort for them to attract friends. I have to work at being social. When we go out it is traumatic..it's a stress. I know it isn't healthy to be so into yourself, I feel like sometimes I am missing out on a lot". On the otherhand, many IC patients anticipated the opportunity to socialize, and "enjoy having friends over and entertaining".

It was also interesting to note that some IC patients expressed a real sensitivity with regards to discussing their physical condition with family, friends or colleagues. "I try to avoid talking about it at all..I think I'd like to hide it from them (friends). Other patients had no difficulty in opening up and talking about their disease, with friends and acquaintances. Again the diversity of personality came through within the interviews, as some IC patients were confident, outgoing and talkative, while other IC patients were shy, and more sensitive in manner.

Psychogenic Attitude Scales

Interstitial cystitis patients as a group scored significantly higher on **recent stress**, **premorbid pessimism** and **somatic anxiety**. While only three of these psychogenic subscales were found to be significant, there seems to be a trend with respect to Chronic

nsion, Social Alienation and Future Despair, as IC patients peared to respond in the same direction across six measures igure 2, Chapter 4).

In terms of the non significant findings, and specifically ronic tension, it was interesting to note that during the terviews, sixty-four (64) percent of IC patients reported periencing upper body tension and forty-five (45) percent reported enching their jaws. This would indicate some form of tension, ich may be reflected and felt physiologically.

Another point of interest was the indication that many IC tients tend to keep their feelings to themselves as well as pressing their anger (see Chapter 4). The physical and emotional nsion noted by IC patients during the interviews may be a very otle difference between the Random Control and IC group.

1. Recent Stress

The effect of stress from the recent past is tapped through this ychogenic attitude sub-scale. As Scott Peck (1978) writes, "Life difficult" (p. 15), and for higher scorers on this scale, there a perception of prevailing stressors and difficulties within the cent past (Millon, Green & Meagher, 1982). According to Millon, een and Meagher (1982) this scale is essentially a enomenological type of assessment very much like the Holmes and he (1967) Social Readjustment Scale and the Saranson, Johnson and egel (1978) Life Expectancy Survey.

Interstitial cystitis patients as a group were significantly different on this measure, and as higher scorers they may tend to feel their past has been notably difficult in numerous settings. Higher scorers also tend to be inordinately sensitive to change, such that when it occurs, they see it negatively.

This somewhat negative point of view combined with life changes, may increase susceptibility to illness or aggravate a chronic health condition (Millon, Green & Meagher, 1982; Rahe & Arthur, 1968; Yunik, 1979).

During the interviews and in response to a question on the ICA Questionnaire, fifty-two (52) percent of those responding, indicated they had experienced stress prior to the onset of interstitial cystitis. In some cases the events were indeed traumatic, while in other instances the stress appeared to be that of day to day living. Lingering effects of a stressful or traumatic event were indicated by many IC patients during the interviews.

In terms of recent stress, one IC patient commented, "I wasn't feeling happy about moving from our new house to a small town and leaving our friends, but I grit my teeth and went with it. Looking back, a lot of things were stressful, but I'd just grit my teeth and take it. I'd pile on a lot of things, but at the time I didn't feel stressed, but maybe I really was- maybe I'd go on nerve. There was my husband's cancer, my hip replacement surgery and my arthritic problems..all before the onset of this condition".

Millon (1982) suggests that in terms of life stress and disease onset, the "real linkage, probably one of moderate proportions, is largely a function of the individual's personal interpretation of the stressful character of events" (p. 15). Interview material and the quantitative results from the MBHI, would seem to suggest that IC patients as a group, may have a perception of having experienced recent stress which may have some impact upon their physical condition.

2. Premorbid Pessimism

As a group, interstitial cystitis patients scored significantly higher on a measure of **premorbid pessimism**. Millon, Green and Meagher (1982), describe this scale as measuring "characterologic tendencies toward viewing the world in a negative manner" (p. 4). Generally higher scorers tend to construe life as a sequence of trials and tribulations, which in turn may heighten any physical or psychological discomfort or distress.

The statements constituting the **premorbid pessimism** sub-scale, portray a "negative attitudinal set" (Millon, 1982 p. 15), with a dispositional attitude of helplessness-hopelessness. Within the IC group, there may perhaps be more of an inclination to be pessimistic in the way life is approached (Millon, Green & Meagher, 1982). To assist in moderating this somewhat negative orientation, it is Millon, Green and Meagher's (1982) suggestion that support and

One middle aged IC patient related an experience from childhood which she feels has colored her perceptions of life situations. Her words were: "My mother was never a very happy person and I can remember growing up if I got excited, she would say - 'Don't get too excited, we may all be dead tomorrow' - which made me feel not too optimistic".

Millon (1982) states that higher scorers on this sub-scale tend to be discontent and "interpret experiences as troublesome and discomforting" (p. 15). Peterson (1988) sought to determine a tendency toward pessimism and illness. Peterson's (1988) findings indicate that a pessimistic style tends to engender a number of negative habits (smoking, drinking, poor nutrition, stressful lifestyle) and probably "low self efficacy to promote one's own health" (p. 130).

Perhaps a diminished sense of internal health control exhibited by interstitial cystitis patients in this study, along with recent stress and a pessimistic style of thinking, may be at odds with fostering overall well-being.

3. Somatic Anxiety

Somatization is a psycho-physiological process where personal or interpersonal distress is conveyed through physical symptoms (Kleinman, 1988; Lipowski, 1987). Kleinman (1988) suggests that cognitive style, personality characteristics, and affective state greatly determine whether a person will "anxiously ruminate" about

Most people encounter some somatization from time to time, however generally little attention is given to bodily sensations. The sensation is typically noted, and then normalized through some form of logical evaluation of the cause.

The chronicity of a disease such as interstitial cystitis, may tend to involve the patient in a more vigilant scanning of bodily processes so as to determine whether the condition that minute or that hour is stable, better or worse.

A number of researchers point out that individuals who score higher on the somatic anxiety scale tend to encounter more fear or concern regarding bodily functions and therefore are more preoccupied with their physical state (Lipsitt, 1970; Lowy, 1977; Lucente & Fleck, 1972; Mechanic & Volkart, 1960; Millon, et al., 1982). Significant results were noted on this scale, as IC patient as a group were distinctly different than the Urinary Tract Infection and Random Control groups.

On the ICA Questionnaire, seventy (70) percent of IC patients responding to a question regarding body symptoms, indicated their symptoms come and go. A persistent monitoring of urinary processes as well as the degree of pain, pressure and frequency focus attention on even the slightest changes in symptoms which could certainly create and amplify somatic as well as S-Anxiety.

Barsky, Wyshak and Klerman (1986) note that a preoccupation with body sensations or changes, a fear of disease, depression,

complaints of the somatizing person. The high percentages obtained from the ICA questionnaire and from interview data (see Chapter 4) suggest that IC patients as a group experience the aforementioned bodily concerns.

In an effort to solve a physical malady, somatizing patients often submit to extensive medical tests, invasive procedures and various therapies which often fail to produce prolonged relief. Many interstitial cystitis patients experience this process at one time or another during the course of the disease, as they search for some pill or treatment to palliate their pain or discomfort.

Again, Millon, et al., (1982) suggest that health care professionals need to "be sensitive to the unwarranted concerns of patients and seek to minimize their consequences by engaging in periodic supportive and reassuring discussions" (p. 4).

Psychosomatic Correlate Scales

Allergic Inclination, Gastrointestinal Susceptibility and **Cardiovascular Tendency** comprise the psychosomatic correlate scales. Interstitial cystitis patients as a group scored significantly higher on all three subscales, than did the Random Control group. Millon, et al., (1982) note that higher scorers find that emotional factors may exacerbate the physical condition in question.

1. **Allergic Inclination**

The allergic inclination sub-scale of the MBHI provides an

indication of how psychosomatic elements may influence or intensify disease process. Ordinarily, this scale is administered to persons diagnosed with various allergic disorders, with the expectation that emotional factors may play a significant role in disease onset.

While there is no conclusive evidence implicating allergens in the onset of IC, a number of researchers have detailed allergic and immunologic indications of interstitial cystitis (Bohne, Hodson, Rebuck, & Reinhard, 1962; Bowers, Schwartz & Leon, 1958; Lose, Frandsen, et al., 1987; Oravisto, Alfthan & Jokinen, 1970).

It is interesting to note that IC patients as a group, scored significantly higher than the Random Control group on the **allergic inclination** sub-scale. Psychological factors may, in some albeit small way influence or aggravate the chronic symptoms experienced by interstitial cystitis patients. Further medical and psycho-social investigation will be needed to clarify whether these factors are truly influential in this disease.

2. **Gastrointestinal Susceptibility**

This sub-scale of the MBHI also provides an indication of how psychological stress might aggravate disease processes. While this scale is recommended for use with individuals diagnosed as having gastrointestinal disorders (ulcers, colitis, dyspepsia), it is interesting to note, that as a group, IC patients are significantly different from the Urinary Tract Infection and the Random Control populations on this dimension.

Bowers, Schwartz and Leon (1958) have noted that many physicians view IC as displaying the same relationship to diseases of the urinary bladder, as ulcerative colitis does to the intestinal tract. Interstitial cystitis may be loosely regarded as an ulcer-like condition of the bladder (Oravisto, 1980).

Certainly the burning frequently associated with stomach ulcers or chronic inflammation of the colon share a similarity with IC. Bowers and Lattimer (1957) noted gastrointestinal disorders occurring in association with interstitial cystitis. Higher scorers on this dimension generally find the course of the disease may worsen, as a result of stressful social or emotional factors.

3. Cardiovascular Tendency

Urologists have alluded to Type A characteristics in female interstitial cystitis patients, primarily from impressions obtained within the patient-physician relationship. In the early stages of her urological practice, Gillespie (1986) considered that Type A behavior patterns, might be associated in some way with interstitia cystitis. Since that time however, she has taken a different view and does not feel that IC patients exhibit such tendencies.
The following comments of IC patients during the interviews, may reflect a characteristic physicians may have noted in talking with IC patients during office visits.

One patient expressed the need or drive to get things done this way: "I am my own worst enemy. I expect to get things done quickly

and I drive myself hard!". Another IC patient expressed these sentiments, "I feel an urgency to get things done at my time, my way!".

It is interesting to note, that a study of thirty-one (31) female interstitial cystitis patients in Finland, revealed higher scores on hostility (Keltikangas-Jarvinen, Auvinen & Lehtonen, 1988). Hostility has been noted as an important psychological risk factor in many somatic diseases as well as heart disease (Eysenck, 1988; Friedman & Rosenman, 1974; Rosenman, Friedman et al., 1966).

As a group, the IC patients in this study scored significantly higher on **cardiovascular tendency**, than did the Random Control group. Certainly the results from this sub-scale would seem to suggest that IC patients as a group may have more of an inclination to cardiovascular tendencies, and therefore may experience increase in symptoms as a result of hyper-sensitivity to emotional stresses or tensions (Millon, et al., 1982).

Further research directed to examining Type A characteristics and the characteristic of hostility noted in the Finnish study (Keltikangas-Jarvinen, Auvinen, & Lehtonen, 1988) will be needed to determine more specifically whether there is some relationship to patients diagnosed with interstitial cystitis.

Prognostic Indices

Interstitial cystitis patients as a group were significantly different on only one of the three prognostic indices scales. As

group, interstitial cystitis patients scored higher than did the Random Control group, on a measure of emotional vulnerability.

Millon, et al., 1982) indicate that higher scorers are generally more negative in their expectations about medical procedures, likely as a result of their lived experience. A more negative outlook in this regard may be counter-productive in treatment planning for IC patients. Many IC patients shared their experiences of consulting several physicians prior to receiving a diagnosis of interstitial cystitis.

"Now that it is diagnosed," said one IC patient, "I feel better about it, but before the diagnosis I felt bitter and resentful. At times I would be scared of it (the IC)".

For many, receiving the correct diagnosis was indeed a relief in finally knowing what was wrong. Over a period of time however, there was for many IC patients, a realization that no medication or medical procedure could guarantee the total alleviation of painful symptoms. The aspect of emotional vulnerability might be best understood from the comments of one IC patient who shared this:

"I've had all kinds of tests, and all the tests they've done a number of times came back inconclusive - so that leads on to another test and another and another. I think as a last resort, the last time I went to see my local urologist, he just threw up his hands and said, "I just don't know what it is..the only thing I can put my finger on, is that it might be interstitial cystitis. My urologist

y knew of that could help this. This is forever!"

Quantitative results from the MBHI, as well as the thoughts and lings expressed by IC patients during interviews, demonstrate the iety and insecurity felt in coping with a disease that has no wn cure or treatment to alleviate all symptoms.

One must also consider that typical medical procedures such as toscopy, dilations and instillations of DMSO into the bladder may o initiate or contribute to feelings of vulnerability and iety. While these are routine treatment modalities, they are en uncomfortable or painful, and for many women may also be tionally distressing or embarrassing.

No group differences were found on **pain treatment responsivity** **life threat reactivity**. In terms of **pain treatment responsivity**, patients as a group scored similarly to the Urinary Tract ection and Random Control groups. This would seem to suggest t IC patients as a group should respond as well to traditional ical treatment programs as would patients in either the Urinary ct Infection or Random Control groups.

Many IC patients reported experiencing considerable pain and comfort (see Chapter 4). The management of chronic and acute is a major concern in most medical practices (Bresler, 1979; ff & Beery, 1985). Ruoff and Beery (1985) make the point that e an organic problem may initially precipitate pain, over time,

oup appear to experience more state anxiety as well as somatic
xiety and these factors may need further research in terms of pain
eatment.

Interstitial cystitis patients may find that at some point
cing the history of their disease, their family, friends or co-
rkers begin to query the authenticity of their chronic pain or
scomfort. During the interviews, a number of IC patients related
at because they may not look physically ill, and because the signs
d symptoms of IC are rather invisible, people may tend to discount
misunderstand the degree of pain or distress characteristic of
is condition.

Concluding Comments

Within the past few years, more and more medical practitioners re coming to see the importance of evaluating both the patient's hysical symptoms, as well as life events, cognitive and emotional eactions of the patient and personality variables which may be nfluential in the course and treatment of disease.

While this study was exploratory, the researcher examined some sychosocial variables and a possible relationship with female atients diagnosed with interstitial cystitis. The literature (see hapter 2) has alluded to a relationship between personality haracteristics and female IC patients, sometimes with a rather egative connotation (Bowers, Schwartz & Leon, 1958; Hand, 1949; unner, 1930; Schwartz, 1925).

The implication that female patients diagnosed with nterstitial cystitis are neurotic or disturbed in some way, may ave been counter-productive in terms of assisting IC patients in oping with the symptoms of their disease. While IC patients as a roup were higher scorers on a number of variables, this does not uggest emotional disturbance nor causality. Further research will e important to assess a number of psychosocial variables in greater epth.

Interstitial cystitis patients were not found to have more trait nxiety, nor were they more irrational in thinking when compared

imilarly, female IC patients were not more externally controlled hen compared with the other two groups within this study.

Significant results were however, noted on several measures. nterstitial cystitis patients as a group displayed more state nxiety, and were more externally controlled in terms of health ttitudes and behaviors.

On a measure of behavioral health attitudes and coping style MBHI), IC patients were found to be significantly different from he Random Control group on seven of the twenty subscales. No one pecific coping style was found to be significant, suggesting that C patients are a heterogeneous group in terms of basic coping tyle, as are persons in the Urinary Tract Infection or Random Control group.

Female IC patients as a group were found to have a perception of experiencing more recent stress. As a group, IC patients also appeared to have a more helpless-hopeless attitude, which may affect the way they approach life. In terms of concern regarding bodily symptoms and sensations, IC patients appear to display more apprehension than did persons in a Random Control or Urinary Tract Infection group.

While the bulk of the hypotheses had to be rejected, there are some interesting findings arising from this study, which will require further research. Specifically, there appear to be several correlates of interstitial cystitis and these are: state anxiety, external health locus of control, somatic anxiety, premorbid

ssimism, and recent stress. As well, IC patients as a group were
gher scorers on measures of cardiovascular tendency,
strointestinal susceptibility, allergic inclination and emotional
nerability.

The need for further research to examine these and other
iables in greater depth, is previewed and discussed in the
lications which follow.

Implications

Mind-body research as it applies to the disease process is
eed complex. As the field of psychoneuroimmunology continues to
and, multi-disciplinary teams will be required to examine disease
sation, in hopes of finding more effective treatments and
sibly cures for chronic disease.

While the orientation of this study was exploratory, it provides
e indications for research into interstitial cystitis. The
lowing recommendations are offered as a result of this study:

It is suggested that future quantitative research probe in greater depth, the variables examined within this study. Health locus of control, pessimism, anxiety, Type A characteristics, and the effects of recent stress, should all receive more detailed investigation. Similarly, data obtained from interview

ychological characteristics of anger, self-esteem, and the
pression of feelings, are related to the interstitial cystitis
sease process, also warrants further study.

ysicians on the whole are becoming more familiar with
nterstitial cystitis and its rather diverse variations. This
due in part to an expanding literature, and the recognition
both an early or non-ulcerative form of IC as well as the
raditional or ulcerative variety. Future researchers will need
o examine differences in patients diagnosed with early,
ntermediate or severe forms of interstitial cystitis. The
lassification of the stage or severity of the disease is seen
o be important in categorizing patients to analyze future data.
erhaps researchers will need to work in concert, to carefully
crutinize these important physiological and psychological
ariables.

nterstitial cystitis patients were found to be higher
corers on a number of variables which suggest they may consider
he benefits of incorporating an adjunctive treatment modality
along with traditional health care to possibly realize greater
control of their physiology. Research studies utilizing
iofeedback, the relaxation response, meditation, visualization
or cognitive therapy would be a starting point to determine the

the alleviation of symptoms or in providing a measure of control for the patient.

The patient-health care team relationship was noted as being of importance in providing reassurance and hope to patients scoring higher on somatic anxiety. As reported in this and previous surveys, interstitial cystitis patients indicate consulting numerous physicians prior to receiving a correct diagnosis and treatment. IC patients were higher scorers on several variables which may be indicative of a need to have a supportive and encouraging health care team with whom to discuss fears and concerns. This issue, as well as the perception of social support should also be examined in greater depth in future investigations.

This study was limited to female interstitial cystitis patients, and as such the results may not be generalized to all IC patients. It will be important for future research to investigate psychosocial correlates with both male and female patients in order to determine similarities and differences in men and women diagnosed with this disease.

The interviews conducted with thirty interstitial cystitis patients, provided an understanding of the real life experience of these women not only in terms of their disease, but in how

talking with patients, suggests that this avenue is a rich and untapped resource. A phenomenological study and analysis is proposed as an area for further research.

This study was focused on psychosocial correlates of interstitial cystitis. What is not clear at this time, is whether these correlates exist because people have the illness or whether they were present in the person prior to the onset of illness. Ultimately, it will be important to set up a research design which could discern more specifically the qualities which may precipitate a chronic illness such as interstitial cystitis. A longitudinal study may be required to explore these complex and multifaceted issues.

REFERENCES

Aboulker, P., & Chertok, L. (1951). *Remarques a propos l'etiologie de la crystalgie a urines claries*. Congres de la Socete Francaise D'urologie. Paris, Summer.

Achterberg, J. (1985). *Imagery in healing; Shamanism and modern medicine*. Massachusetts: Shambhala Publications.

Ader, R. (1985). Behaviorally conditioned modulation of immunity. I T. Guillemin, M. Cohn, & T Melnechuk (Eds.), *Neural modulation of immunity*. New York: Raven Press.

Ader, R. (1983). Developmental psychoneuroimmunology. *Developmental Psychobiology*, **16** , 251-267.

Ader, R. (Ed.) (1981). *Psychoneuroimmunology*. New York: Academic Press.

Ader, R., & Cohen, N. (1982). Behaviorally conditioned immunosuppression and murinesystemic lupus erythematosus. *Psychosomatic Medicine*, **44** , 127-128.

Agnew, N., & Pyke, S. W. (1987). *The science game, An introduction to research in the social sciences*. New Jersey: Prentice Hall.

Ahluwalia, P., Zaacharko, R. M., & Anisman, H. (1985). *Doppamine variations associated with acute and chronic stressors*. Presentatio at the annual meeting of the society of Neuroscience, Dallas, October.

Aldenborg, F., Fall, M., & Enerback, L. (1986). Proliferation and transepithelial migration of mucosal mast cells in interstitial cystitis. *Immunology*, **58** , 411-416.

Alexander, F. (1950). *Psychosomatic medicine*. New York: W. W. Norton.

Allen, S. (1970). Homogeneity and separability of irrational beliefs. Unpublished master's thesis, University of Alberta, Edmonton.

Alloy, L. B., Peterson, C., Abramson, L. Y., & Seligman, M. E. P. (1984). Attributional style and generality of learned helplessness *Journal of Personality and Social Psychology*, **46** , 681-687.

Almy, T. P., Kern, F., & Abbot, F. (1950). Constipation and diarrhea. *Assoc. Res. Nerv. and Ment. Dis.; Proc.*, **29** , 724.

Anderson, J. B., Parivar, F., Lee, G., Wallington, T. B., MacIver, A. G., Bradbrook, R. A., & Gingell, J. C. (1989). The enigma of interstitial cystitis - an autoimmune disease? *British Journal of Urology*, 63 , 58-63.

Antonovsky, A. (1987). *Unraveling the mystery of health. How people manage stress and stay well*. California: Jossey-Bass.

Antonovsky, A. (1984). The sense of coherence as a determinant of health. In J. D. Matarazzo, S. M. Weiss, J. A. Herd, N. E. Miller, (Eds.), *Behavioral Health: A handbook of health enhancement and disease prevention*. New York: Wiley.

Antonovsky, A. (1979). *Health, Stress and Coping*. California: Jossey-Bass.

Baker, G. H. B. & Brewerton, D. A. (1981). Rheumatoid arthritis: a psychiatric assessment. *British Medical Journal*, 282 , 2014.

Bandura, A. (1985). Catecholamine secretion as a function of perceived coping self-efficacy. *Journal of Counselling and Clinical Psychology* , 58 (3), 406-414.

Barsky, A. J., Wyshak, G., & Klerman, G. L. (1986). Medical and psychiatric determinants of outpatient medical utilization. *Medical Care*, 24 , 548-563.

Beecher, H. K. (1956). Relationship of significance of would to pain experienced. *Journal of the American Medical Association*, 161 (17), 1609-1613.

Beecher, H. K. (1955). The powerful placebo. *Journal of the American Medical Association*, 159 (17), 1602-1606.

Benson, Herbert. (1984). *Beyond the relaxation response*. New York: Berkley Publishing Company.

Benson, Herbert. (1975). *The relaxation response*. New York: Avon.

Bernstein, I. W. (1973). Immunologic defenses against cancer. *Journal of Pediatrics*, 87 , 906-918.

Bernstein, I. W. (1971). Tumor immunity: impairment in tumor-bearing host. *Journal of the National Cancer Institute*, 46 , 873-880.

Bohne, A. W., Hodson, J. M., Rebuck, J. W., & Reinhard, R. E. (1962). An abnormal leukocyte response in interstitial cystitis. *Journal of Urology*, 88 , 387.

Borysenko, J. (1987). *Minding the body, mending the mind*.

Borysenko, J. (1984). Stress, coping and the immune system. In J. D. Matarazzo, S. M. Weiss, J. D. Herd, J. D. Miller (Eds.), *A Handbook of Health Enhancement and Disease Prevention*. New York: John Wiley & Sons.

Bowers, J. E., & Lattimer, J. K. (1957). Interstitial cystitis. *Surgery, Gynecology and Obstetrics*, 105 , 313-322.

Bowers, J. E., Schwartz, B. E., & Leon, M. J. (1958). Masochism and interstitial cystitis: A case report. *Psychosomatic Medicine*, 20 , 296.

Bresler, D. E. (1979). *Free yourself from pain*. New York: Simon & Schuster.

Bresler, D., & Rossman, M. (1988). Imagery in healing audio tapes. Phase I training tapes, California.

Brown, Barbara. (1984). *Between health and illness*. Massachusetts: Houghton Mifflin Company.

Brown, Barbara. (1980). *Supermind: The ultimate energy*. New York: Harper & Row.

Bry, A., & Blair, M. (1978). *Directing the moves of your mind*. New York: Harper & Row.

Bull, N. (1945). Toward a clarification of the concept of emotion. *Psychosomatic Medicine*, 7 , 210.

Campbell, D. T. (1963). Social attitudes and other acquired behavioral dispositions. In S. Koch (Ed.), *Psychology of a science*. 6 , (pp. 94-172). New York: McGraw-Hill.

Cannon, W. (1945). *The way of an investigator*. New York: W. W. Norton.

Cannon, W. (1939). *The wisdom of the body*. New York: W. W. Norton.

Cannon, W. (1929). *Bodily changes in pain, hunger, fear and rage*. Boston: Charles T. Branford Company.

Cattell, R. B., & Scheier, I. H. (1963). *Handbook for the IPAT Anxiety Scale (2nd. Ed.)*. Champaign Illinois: Institute for Personality and Ability Testing.

Chenowith, C. V., & Claywater, E. W. (1960). Interstitial cystitis in children. *Journal of Urology*, 83 , 150-152.

Cousins, N. (1983). *The healing heart*. New York: Norton.

Cousins, N. (1981). *Human options*. New York: Berkeley Publishing Company.

Cousins, N. (1979). *Anatomy of an illness as perceived by the patient*. New York: Norton.

Cox, T. (1978). *Stress*. New York: MacMillan.

Davies, R. L. & Zingle, H. W. (1970). Adult irrational ideas inventory. Unpublished manuscript, University of Alberta, Edmonto

Dees, J. E. (1953). Use of cortisone in interstitial cystitis: Preliminary report. *Journal of Urology*, 69 , 496-502.

Dorian, B., & Garfinkel, P. E. (1987). Stress, immunity and illne - a review. *Psychological Medicine* , 17 , 393-407.

Dossey, L. (1982). *Space, time and medicine*. Massachusetts: Shambhala Publication.

Dunbar, F. (1954). *Emotions and bodily changes*. New York: Columbi University Press.

Dunbar, F. (1947). *Mind and body: Psychosomatic medicine*. New Yor Random House.

Dunbar, F. (1943). *Psychosomatic diagnosis*. New York: Harper & Ro

Edwards, L., Bucknall, T. E., & Makin, C. (1986). Interstitial cystitis: Possible cause and clinical study of sodium cromoglycat *British Journal of Urology*, 58 , 95-96.

Eliot, R. S., & Breo, D. L. (1984). *Is it worth dying for ?* Toronto: Bantam Books.

Ellis, A. (1984). The essence of RET - 1984. *Journal of Rational Emotive Therapy*, 2 , 19-25.

Ellis, A. (1978). Atheism: A cure for neurosis. *American Atheist* (3), 10-13.

Ellis, A. (1962). *Reason and emotion in psychotherapy*. New York: Lyle Stewart.

Enerback. L., Fall, M., & Aldenborg, F. (1989). Histamine and mucosal mast cells in interstitial cystitis. *Agents and Actions*,

Engel, G. L. (1971). Sudden and rapid death during psychological stress. *Annals of International Medicine*, **74** , 771-782.

Everly, G. S. (1989). *Guide to the treatment of the human stress response*. New York: Plenum Press.

Everly, G. S., & Rosenfeld, R. (1981). *The nature and treatment of the stress response: Practical guide for clinicians*. New York: Plenum.

Eysenck, H. (1988). Health's Character. *Psychology Today*, **December** 28-35.

Eysenck, H. (1987). Anxiety, learned helplessness and cancer: A causal theory. *Journal of Anxiety Disorders*, **Vol.** 1 , 87-104.

Eysenck, H. (1985). Personality, cancer and cardiovascular disease A causal analysis. *Personality and Individual Differences*, **5** , 535 537.

Feltis, J. T., Perez-Marrero, R., & Emerson, L. E. (1987). Mast cells of bladder in suspected cases of interstitial cystitis: Possible disease marker. *Journal of Urology*, **138** , 42.

Ferguson, G. (1981). *Statistical analysis in psychology and education (5th ed.)*. Toronto: McGraw-Hill.

Friedman, A. P., & Rosenman, R. H. (1974). *Type A behavior and you heart*. New York: Alfred A. Knopf.

Fox, B. H. (1983). Current theory of psychogenic effects on cancer incidence and prognosis. *Journal of Psychosocial Oncology*, **I** , 17- 32.

Gallagher, W. (1986). The dark affliction of mind and body. *Discover*, **May** , 73.

Galli, S. J., Dvorak, A. M., & Dvorak, H. P. (1984). Basophils and mast cells. Morphologic insights into their biology, secretory patterns and function. *Progress in Allergy*, **34** , 1-83.

Geist, R. W., & Antolak, S. J. Jr. (1970). Interstitial cystitis i children. *Journal Urology*, **104** , 922-925.

Ghanta, V., Hiramoto, R., Solvason, H., & Spector, N. (1985). Neur and environmental influence on neoplasia and conditioning of the N activity. *Journal of Immunology*, **135** (2), 848-852.

Gillespie, L. (1986). *You don't have to live with cystitis*. New York: Rawson Associates.

Good, I. J. (1983). The philosophy of exploratory data analysis. *Philosophy of Science*, 50 , 283-295.

Good, R. A. (1981). Forward: Interactions of the body's major networks. In R. Ader (Ed.)., *Psychoneuroimmunology*, New York: Academic Press.

Gorczynski, R., Macrae, S., & Kennedy, M. (1982). Conditioned immu response associated with allogenic skin grafts in mice. *Journal of Immunology*, 129 , 704-709.

Gottschalk, L. A., & Gleser, G. C. (1969). *The measurement of psychological states through the content analysis of verbal behavior*. Berkeley: University of California Press.

Grace, W. J., & Graham, D. T. (1952). Relationship of specific attitudes and emotions to certain bodily diseases. *Psychosomatic Medicine*, 14 , 243-251.

Graham, D. T., Lundy, R. M., & Benjamin, L. S. (1962). Specific attitudes in initial interviews with patients having different psychosomatic diseases. *Psychosomatic Medicine*, 24 , 257-266.

Green, A., & Green, E. (1975). *Beyond Biofeedback*. New York: Delta/Dell.

Green, C. (1982). Psychological assessment in medical settings. In T. Millon, C. Green, & R. Meagher (Eds.), *Handbook of Clinical Health Psychology* (pp 339-376). New York: Plenum Press.

Groen, J. (1947). Psychogenesis and psychotherapy of ulcerative colitis. *Psychosomatic Medicine*, 9 , 151.

Grossarth-Maticek, R., Kanazir, D. T., Schmidt, P., & Vetter, H. (1985). Psychosocial and organic variables as predictors of lung cancer, cardiac infarct and apoplexy: some differential predictor *Personality and Individual Differences*, 6 , 313-320.

Grossarth-Maticek, R., Kanazir, D. T., Vetter, H., & Jankovic, M. (1983). Smoking as a risk factor for lung cancer and cardiac infa as mediated by psychosocial variables. A prospective investigatio *Psychotherapy Psychosomatics*, 39 , 94-105.

Grossarth-Maticek, R., Kanazir, D. T., Schmidt, P., & Vetter, H. (1982). Psychosomatic factors in the process of cancerogenesis.

Browald, E. R. (1985). "Health and wholeness: The
Mystery". *Advances*, 2 , Fall 4-10.

Guerrier, H. P., Roberts, J. P. M., & Slade, N. (
Inflammatory agents in the management of interstit
British Journal of Urology, 35 , 88-92.

Hall, H (1982-1983). Hypnosis and the immune syst
Implications for cancer and the psychology of heal
Journal of Clinical Hypnosis, 25 (2-3), 92-103.

Hall, M. D. (1983). Using relaxation imagery with
malignancies: A developmental perspective. *Americ
Clinical Hypnosis*, 25 (2-3), 143-149.

Hamburg, D. A., Elliot, G., & Parron, D. L. (Eds.
and behavior: Frontiers of research in the biobeh
Washington, D. C., National Academy Press.

Hand, J. R. (1949). Interstitial cystitis. Report
women and 19 men). *Journal of Urology*, 61 , 291-3

Hanno, P. M. (1989). Interstitial cystitis: When
it? What can you do about it? *Emergency Medicine*
156.

Hanno, P. M., Levin, R. M., Monson, F. C., Teusch
Z., Ruggieri, M., Whitmore, & Wein, A. J. (1990).
Interstitial cystitis. *Journal of Urology*, 143 ,

Hanno, P. M., & Wein, A. J. (1987). *Interstitial*
Urologic Association Update Series .

Harrison, J. H., Gittes, R., & Perlmutter, A. (19
Campbell's Urology (5th ed.).

Harrison, J. H., Gittes, R., & Perlmutter, A. (19
Campbell's Urology (4th ed.).

Held, P., Hanno, P., Wein, A., & Pauly, M. (1987)
national institute of arthritis, diabetes, digest
diseases workshop on interstitial cystitis, natio
health, Bethesda, Maryland, Aug. 28-29, 1987. *Jou*
140 , 203-208.

mind-body

1965). Anti-
cial cystitis.

tem: A review with
ling. *The American*

children with
an Journal of

) (1982). *Health*
avioral sciences.

of 223 cases (204
10.

should you suspect
, 21 (11), 149-

er, C., Zhou, Z.
Diagnosis of
278-281.

Cystitis. American

86) (Eds.),

79) (Eds.),

. In summary of the
ive and kidney
nal institutes of
rnal of Urology,

ebert, B. (1983). A framework for planning stress control tervention. *Canadian Counsellor*, 17 , 51-61.

ppocrates. (1938). *Works of Hippocrates Volume 3*. New York: dical Classics.

lm-Bentzen, M., & Lose, G. (1987). Pathology and pathogenesis of terstitial cystitis. *Supplement to Urology*, 29 (4), 8-13.

lmes, T. H., & Rahe, R. (1967). The social readjustment rating ale. *Journal of Psychosomatic research*, 11 , 213-218.

nner, G. L. (1930). Neurosis of the bladder. *Journal of Urology*, , 567-585.

nner, G. L. (1915). A rare type of bladder ulcer in women: Report cases. *Boston Medical Journal*, 172 , 660-662.

nzen, H. L., & Beeken, D. (1973). Analysis of the applicability of e locus of control construct. *The Alberta Journal of Educational search*, 19 , 295-302.

mmott, J. B., & Locke, S. E. (1984). Psychosocial factors, mmunological mediation and human susceptibility to infectious seases: How much do we know? *Psychological Bulletin*, 75 , 78-108.

hnson, S. (1985). *One Minute for myself*. New York: William Morrow d Company.

kinen, E. J., Alfthan, O. S., & Oravisto, K. J. (1972). Antitissue tibodies in interstitial cystitis. *Clinical and Experimental mmunology*, 11 , 333-339.

rdan, S. C., & Lenington, K. T. (1979). Psychological correlates eidetic imagery and induced anxiety. *Journal of Mental Imagery*, , 31-42.

ng, C. G. (1964). *Man and his symbols*. London: Aldus Books.

stice, B. (1988). *Who gets sick* . California: Jeremy Tarcher, Inc.

men, L. P., & Seligman, M. E. P. (1987). Explanatory style and alth. *Current Psychological Research and Reviews*, 6 (3), 207-218.

sl, S. V. (1984). Stress and health. In L.Breslow, J. E. Fielding

eltikangas-Jarvinen, L., Auvinen, L., & Lehtonen, T. (1988). sychological factors related to interstitial cystitis. *European rology*, 15 , 69-72.

iecolt-Glaser, J. K., Stephens, R. E., Lipetz, P. D., Speicher, C. ., & Glaser, R. (1985). Distress and DNA Repair in human ymphocytes. *Journal of Behavioral Medicine*, 8 , 311-320.

issen, D. M. (1967). Psychosocial factors, personality and lung ancer in men aged 55-64. *British Journal of Medical Psychology*, , 29-43.

issen, D. (1963). Personality characteristics in males conducive to ung cancer. *British Journal of Medical Psychology*, 36 , 27-48.

einman, A. (1988). *The illness narratives*. New York: Basic Books nc.

obasa, S. (1979). Stressful life events, personality and health! ournal of Personality and Social Psychology, 37 , 1-11.

obasa, S. C., Maddi, S. R., & Courington, S. (1981). Personality nd constitution as mediators in the stress-illness relationship. ournal of Health and Social Behavior, 22 , 368.

obasa, S. C., Maddi, S. R., & Kahn, S. (1982). Hardiness and ealth. *Journal of Perspective Social Psychology*, 42 , 168-177.

orneva, E. A., Klimenko, V. M., & Shkhinek, E. R. (1985). eurohumoral maintenance of immune homeostasis. Chicago: University f Chicago Press.

anger, E. J. (1983). *The psychology of control*. California: Sage.

anger, E. J., Jonis, I. L., & Wolfer, J. A. (1975). Reduction of sychological stress in surgical patients. *Journal of Experimental ocial Psychology*, 11 , 155-165.

azarus, R. S., & Opton, E. M. (1966). The study of psychological tress: A summary of theoretical formulations and experimental indings. In C. D. Spielberger (Ed.), *Anxiety and Behavior*. New York cademic Press. 225-262.

oCrone, H. (1979). *Parting with pain*. Texas: Self-Control Systems.

Levenson, H. (1973). Multidimensional locus of control in psychiatric patients. *Journal of Consulting and Clinical Psychology*, 41 , 397-404.

Levine, J. D., Gordon, N. C., & Fields, H. L. (1978). The mechanism of placebo analgesia. *The Lancet*, **September** , 654-657.

Lipowski, Z. J. (1987). Somatization: The experience and communication of psychological distress as somatic symptoms. *Psychotherapy Psychosomatics*, 47 , 160-167.

Lipsitt, D. L. (1970). Medical and psychological characteristics of "crocks". *International Journal of Psychiatry in Medicine*, 1 , 15-25.

Locke, S., & Colligan, D. (1986). *The healer within: The new medicine of mind and body*. New York: E. P. Dutton.

Locke, S., Kraus, L., Lesserman, J., Hurst, M., Heisel, S., & Williams, R. (1984). Life change stress, psychiatric symptoms, and natural killer-cell activity. *Psychosomatic Medicine*, 46 , 441-453.

Lose, G., Frandsen, B., Holm-Bentzen, M., Larsen, S., & Jacobsen, F. (1987). Urine esinophil cationic protein in painful bladder disease. *British Journal of Urology*, 60 , 39-42.

Lowy, F. H. (1977). Management of the persistent somatizer. In Z. J. Lipowski, D. R. Lipsitt, & P. C. Whybrow (Eds.), *Psychosomatic Medicine: Current Trends and Clinical Applications*. New York: University Press.

Lucente, F. E., & Fleck, S. A. (1972). A study of hospitalization anxiety in 408 medical and surgical patients. *Psychosomatic Medicine*, 34 , 304-312.

Lynes, W. L., Flynn, S. D., Shortliffe, L. D., Lemmers, M., Zipser, R., Roberts, J., & Stamey, T., (1987). Mast cell involvement in interstitial cystitis. *Journal of Urology*, 138 , 746-752.

MacLean, P. D. (1949). Psychosomatic disease and the visceral brain. *Psychosomatic Medicine*, 11 , 350.

Maddi, S. R., & Kobasa, S. C. (1984). *The hardy executive: Health under stress*. Illinois: Dow Jones-Irwin.

Magnusson, D. (1982). Situational determinants of stress: An

Maguire, T. O. (1986). Applications of new directions in statistics to educational research. *The Alberta Journal of Educational Research*, 32, (2), 154-171.

Mastrovito, R. C., Deguire, K. S., Clarkin, J., Thaler, T., Lewis, J.L., & Cooper, E. (1979). Personality characteristics of women with gynecological cancer. *Cancer Detection and Prevention*, 2 (2), 281-287.

McCormick, N. B., & Vinson, R. K. (1989). Stresses faced by caregivers, the family members and friends who help IC patients cope. *ICA Update*, Winter, 1-9.

McCormick, N. B., & Vinson, R. K. (1989). Interstitial cystitis: How women cope. *Urological Nursing*, April-June, 13-17.

McCormick, N. B., & Vinson, R. K. (1988). Sexual difficulties experienced by women with interstitial cystitis. *Women and Therapy*, 7 (#2-3), 2-15.

McDonald, H. P., Upchurch, W., & Sturdivant, C. E. (1953). Interstitial cystitis in children. *Journal of Urology*, 70 , 890.

McIntosh, J. H., Nasiry, R. W., Frydman, M., Waller, S. L., & Piper, J. W. (1983). The personality patterns of patients with chronic peptic ulcer. A case-control study. *Scandinavian Journal of Gastroenterology*, 18 , 945-950.

Meares, E. (1987). Guest editorial: Interstitial cystitis. *Supplement to Urology*, April (4), 46.

Mechanic, D., & Volkart, E. H. (1960). Stress, illness behavior and the sick role. *American Sociological Review*, 26 , 51.

Menninger, K. A. (1946). *The human mind*. New York: Alfred Knopf.

Menninger, K. (1938). *Man against himself*. New York: Harcourt, Brace & Company.

Messing, E. M. (1986). Interstitial cystitis and related syndromes in *Campbell's Urology*, P.C. Walsh, R. F Gittes, A. D. Perlmutter, T. A. Stamey, Vol. 1, Fifth Edition.

Messing, E. M. & Stamey, T. A. (1978). Interstitial cystitis: Early diagnosis, pathology and treatment. *Urology*, 12 , 381-392.

Millon, T. (1977). *Millon clinical multiaxial inventory manual*. Minneapolis: National Computer Systems.

Millon, T. (1969). *Modern psychopathology*. Philadelphia: Saunders.

Millon, T., Green, C., & Meagher, R. (1982). *The millon behavioral health inventory (MBHI) manual* (3rd ed.). Minneapolis: National Computer Systems.

Millon, T., Green, C. & Meagher, R. (1979). The MBHI manual: A new inventory for the psycho diagnostician in medical settings. *Professional Psychology*, 10 , 529-539.

Montassut, M., Chertok, L., & Abouker, P. (1951). De quelques inestigations psychiatriques enurologie. *Semaine Hop.*, 27 , 3002-3005.

Moos, R. H., & Solomon, G. F. (1964). Minnesota multiphasic personality inventory response patterns in patients with rheumatoid arthritis. *Journal of Psychosomatic Research*, 8 , 17-28.

Nathan, R. (1985). as quoted by Maness, B., Staying fit: Physician heal thyself. The Continental, November, 11.

Norusis, M. J. (1983). *SPSS - introductory statistics guide*. New York: McGraw-Hill.

Nyberg, L. (1988). National Institutes of Health, Bethesda Maryland, Chairman of the Interstitial Cystitis Program, Division of Kidney, Urologic and Hematologic Diseases. Personal communication, November.

O'Regan, B. (1988). Disease, causality and the mind. *Noetic Sciences Review*, Summer (7) , 21-22.

Oravisto, K. J. (1975). Epidemiology of interstitial cystitis. *Annales Chirurgiae Gynaecologiae Fenniae (Helsinki)*., 64 , 75-77.

Oravisto, K. J. (1980). Interstitial cystitis as an autoimmune disease. A review. *European Urology*, 6 , 10-16.

Oravisto, K. J., Alfthan, O. S., & Jokinen, E. J. (1970). Interstitial cystitis. Clinical and immunological findings. *Scandinavian Journal of Urology-Nephrology*, 4 , 37.

Ornstein, R., & Sobel, D. (1987). *The healing brain*. New York: Simon & Schuster.

Parsons, C. L. (1987). Sodium pentosanpolysulfate - treatment of interstitial cystitis: An update. *Supplement to Urology*, April, Vol. XXIX, #4, 14-16.

Paul, S. (1986). As quoted by Gallagher. The dark affliction of mind and body. *Discover*, May, 76.

Pearsall, P. (1987). *Superimmunity: Master your emotions and improve your health*. New York: McGraw-Hill Book Company.

Peck, M. Scott. (1978). *The road less travelled. A new psychology of love, traditional values and spiritual growth*. New York: Touchstone, Simon & Schuster.

Pert, C. B. (1986a). "The wisdom of receptors: Neuropeptides, the emotions and bodymind". *Advances*, 3, 8-16.

Pert, C. (1986b). Put "closet" interest in consciousness led her to opiate findings: Pursuit of Peptides opens doors. *Brain/Mind Bulletin*, January 20, 2.

Pert, C. B., Ruff, M. R., Weber, R. J., & Heikenham, M. (1985). Neuropeptides and their receptors: A psychosomatic network. *Journal of Immunology*, 135 (2), 820-826.

Peterson, C. (1988). Explanatory style as a risk factor for illness. *Cognitive Therapy and Research*, 12 , 117-130.

Peterson, C., & Seligman, M. E. P. (1987). Explanatory style and illness. *Journal of Personality*, 55 (2), 237-265.

Peterson, C., Seligman, M. E. P., & Vaillant, G. E. (1988). Pessimistic explanatory style is a risk factor for physical illness: A thirty-five year longitudinal study. *Journal of Personality and Social Psychology*, 55 (1), 23-27.

Porter, A. C., & Raudenbush, S. W. (1987). Analysis of covariance: It's model and use in psychological research. *Journal of Counseling psychology*, 34 (4), 383-392.

Rahe, R. H., & Arthur, R. J. (1968). Life change patterns surrounding illness experience. *Journal of Psychosomatic Research*, 11 , 341-345.

Ratner, V. (1987). Rediscovering a "rare" disease: A patient's perspective on interstitial cystitis. *Supplement to Urology*, Vol. XXIX, #4 , 44-45.

Rodin, J. (1979). Managing the stress of aging: The role of control and coping. In S. Levine & U. Holger (Eds.), *Coping and Health*. New York: Plenum.

Rodin, J., Rennart, K., & Solomon, S. K. (1980). Intrinsic motivation for control: Fact or fiction. In A. Baum & J. E. Singer (Eds.), *Advances in Environmental Psychology, Vol. 2: Application of Personal Control*. Hillsdale, New Jersey: Erlbaum.

Rogers, M. P., Dubey, D., & Reich, P. (1979). The influence of the psyche and the brain on immunity and disease susceptibility: A critical review. *Psychosomatic Medicine*, 41 , 147-164.

Rose, Jeanne. (1989). Interstitial cystitis no laughing matter. *Indianapolis Woman*, January, 49-51.

Rosenman, R. H., Friedman, M., Strauss, R., Wurm, M., Jenkins, J. D., Messinger, H., & Kositchek, R. (1966). Western collaboratory group study. *Journal of American Medicine*, 195 , 86-98.

Rossi, E. (1986). *The psychology of mind-body healing. New concepts of therapeutic hypnosis*. New York: W. W. Norton & Company.

Rossman, M. (1988). The healing power of imagery. *New Age Journal*, March/April, 46-56.

Rossman, M. L. (1987). *Healing Yourself*. New York: Pocket Books.

Rossman, M. L. (1984). Imagine Health! Imagery in Medical Self-Care. In A. A. Sheikh (Ed.), *Imagination and Healing*. New York: Baywood Publishing Company.

Rotter, J. B. (1966). Generalized expectancies for internal versus external control of reinforcement. *Psychological Monograph*, 80 , 609.

Ruoff, G. E., & Beery, G. B. (1985). Chronic pain. Characteristics, assessment, and treatment plans. *Postgraduate Medicine*, 78 (4), 91-97.

Sant, G. R. (1989). Interstitial cystitis: Pathophysiology, clinical evaluation and treatment. *Urology Annual*, 3 , 171-196.

Saranson, I. G., Johnson, J., & Siegel, J. (1978). Assessing the impact of life changes. *Journal of Consulting and Clinical Psychology*, 46 , 932-946.

Scheier, M. F., & Carver, C. S. (1987). Dispositional optimism and physical well-being: The influence of generalized outcome expectancies on health. *Journal of Personality*, 55 (2), 169-210.

Scherg, H., Cramer, I., & Blohmke, M. (1981). Psychosocial factors and breast cancer: A critical re-evaluation of established hypotheses. *Cancer Detention and Prevention*, 4 , 165-171.

Schmale, A. H., & Iker, H. P. (1966a). The affect of hopelessness and the development of cancer: Identification of uterine cervical cancer in women with atypical cytology. *Psychosomatic Medicine*, 28 , 714-721.

Schmale, A. H., & Iker, H. P. (1966b). The psychological setting of uterine cervical cancer. Annals of the New York Academy of *Science*, 125 , 807-813.

Schmidt, A. (1981). Application of the social ecological approach to compliance with hemodialysis treatment. Unpublished doctoral dissertation, University of Windsor, Ontario.

Schwartz, D. (1987). In summary of the national institute of arthritis, diabetes, digestive and kidney diseases workshop on interstitial cystitis, national institutes of health, Bethesda, Maryland, August 28-29. *Journal of Urology*, 140 , 203-208.

Schwarz, O. (1925). Psychogene Miktions storungen. In Schwarz, O., *Psychogenesse and Psychotherapie Korperlicher Symptome*. Wein: Springer, 273-294.

Seligman, M. E. P., & Schulman, P. (1986). Explanatory style as a predictor of productivity and quitting among life insurance sales agents. *Journal of Personality and Social Psychology*, 50 (4), 832-838.

Selye, H. (1956). *The stress of life*. New York: McGraw-Hill.

Selye, H. (1946). The general adaptation syndrome and the diseases of adaptation. *Journal Clinical Endocrinology*, 6 , 117.

Shavelson, R. J. (1988). *Statistical reasoning for the behavioral sciences*. Massachusetts: Allyn and Bacon Inc.

Siegel, B. (1989). *Peace, love, and healing*. New York: Harper & Row.

Siegel, B. (1986). *Love, medicine and miracles*. New York: Harper & Row.

Siever, L. J., & Davis, K. L. (1985). Overview: Toward a

Silk, M. R. (1970). Bladder antibodies in interstitial cystitis. *Journal Urology*, **103** , 307-309.

Simonton, O. C., Simonton, S. M., & Creighton, J. L. (1978). *Getting well again*. New York: Bantam Books.

Sklar, L. S. & Anisman, H. (1979). Stress and coping factors influence tumor growth. *Science*, **205** , 513-515.

Slade, D. K. A. (1989). Interstitial cystitis: A challenge to urology. *American Urological Association Allied Journal Urologic Nursing*, 9 (3), 5-7.

Solomon, G. (1985). The emerging field of psychoneuroimmunology with a special note on AIDS. *Advances*, Winter (2) , 6-19.

Spielberger, C. D. (1983). *State-trait anxiety inventory: A comprehensive bibliography*. Palo Alto, California: Consulting Psychologists Press.

Spielberger, C. D. (1966). *Anxiety and Behavior*. New York: Academic Press.

Spielberger, C. D., Gorusch, R. L., & Lushene, R. E. (1984). State-trait anxiety inventory. In D. J. Keyser & R. C. Sweetland (Eds.), *Test Critiques*, Volume 1 (pp. 626-632).

Stein, M., Keller, S., & Schleifer, S. (1985). Stress and immunomodulation: The role of depression and neuroendocrine function. *The Journal of Immunology*, **135** (2), 827-833.

Stevens, J. (1986). *Applied Multivariate statistics for the social sciences* (pp. 290-325). New Jersey: Lawrence Erlbaum.

Straub, L. R., Ripley, H. S., & Wolf, S. (1949). Disturbances of bladder function with emotional states. *Journal of the American Medical Association*, **141** , 1139-1143.

Stroebel, C. (1982). *The quieting reflex*. New York: G. P. Putnam & Sons.

Taylor, J. A. (1953). A personality scale of manifest anxiety. *Journal of Abnormal and Social Psychology*, **48** , 285-290.

Tennen, H., & Affleck, G. (1987). The costs and benefits of optimistic explanations and dispositional optimism. *Journal of Personality*, **55** (2), 376-393.

Visintainer, M. A., Volpicelli, J. R., & Seligman, M. E. P. (1982). Tumor rejection in rats after inescapable or escapable shock. *Science*, **216** , 437-439.

Wallston, K. A., Wallston, B. S., & DeVellis, R. (1978). Development of the multidimensional health locus of control (MHLC) scales. *Health Education Monographs*, **6** (2), 160-170.

Walsh, A. (1978). Interstitial cystitis. In J. H. Harrison, R. F. Gittes, A. D. Perlmutter, T. A. Stamey, & P. C. Walsh (Eds.), *Campbell's Urology* (4th ed.). Philadelphia: W. B. Saunders, 693-707.

Weaver, R. G., Dougherty, T. F., & Natoli, A. (1963). Recent concepts of interstitial cystitis. *Journal of Urology*, **89** , 377-383.

Weiss, J. M., Glazer, H. I., Pohorecky, L. A., Bailey, W. H., & Schneider, L. H. (1979). Coping behavior and stress-induced behavioral depression. In R. A. Depue (Ed.), *The Psychology of the Depressive Disorders*. New York: Academic Press.

Winefield, H. R. (1982). Reliability and validity of the health locus of control scale. *Journal of Personality Assessment*, **46** , 614-619.

Wirsching, M., Stierlin, H., Hoffman, F., Weber, G., & Wirsching, B. (1982). Psychological identification of breast cancer patients before biopsy. *Journal of Psychosomatic Research*, **26** , 1-10.

Wooley-Hart, A. (1979). Meditation and cancer. Slowing down the inevitable. *Nursing Mirror*, **149** (14), 36-39.

Worth, P. H. L., & Turner-Warwick, R. (1973). The treatment of interstitial cystitis by cystolysis with observations on cystoplasty. *British Journal of Urology*, **45** , 65.

Yunik, S. (1979). The relationship of personality variables and stressful life events to the onset of physical illness. Unpublished doctoral dissertation, University of Miami, Florida.

Zingle, H. W., A rational therapy approach to counseling underachievers. Unpublished Doctoral Dissertation, University of Alberta, 1965.

APPENDIX A

QUESTIONNAIRES AND DEMOGRAPHIC DATA

The Questionnaires which follow in the test booklet are as follows:

Part One	State-Trait Anxiety Inventory
Part Two	Adult Irrational Ideas Inventory
Part Three	Internal-External Locus of Control
Part Four	Multidimensional Health Locus of Co
Part Five	Millon Behavioral Health Inventory

University
of
Alberta

Interstitial Cystitis Study

The following questions are designed to gain further understanding of this condition.

Your time and assistance in completing the material within, is very much appreciated.
Please answer all questions frankly and honestly.
All responses are CONFIDENTIAL

SECTION A

A number of statements which people have used to describe themselves in a work situation, are given below.

Read each of them and circle the number which indicates how you feel when you are at work (if you are a homemaker and manager of your household, please answer in terms of performing your household duties)

There are no right or wrong answers.

Do not spend too much time on any one statement but give the answer which seems to describe your feelings.

1	Not at all
2	Somewhat
3	Moderately so
4	Very much so

1.	I feel calm.	1	2	3	4
2.	I feel secure.	1	2	3	4
3.	I am tense.	1	2	3	4
4.	I feel strained.	1	2	3	4
5.	I feel at ease.	1	2	3	4
6.	I feel upset.	1	2	3	4
7.	I am presently worrying over possible misfortunes.	1	2	3	4
8.	I feel satisfied.	1	2	3	4
9.	I feel frightened.	1	2	3	4

12.	I feel nervous.	1	2	3	4
13.	I am jittery.	1	2	3	4
14.	I feel indecisive.	1	2	3	4
15.	I am relaxed.	1	2	3	4
16.	I feel content.	1	2	3	4
17.	I am worried.	1	2	3	4
18.	I feel confused.	1	2	3	4
19.	I feel steady.	1	2	3	4
20.	I feel pleasant.	1	2	3	4

Section B

A number of statements which people have used to describe themselves are given below.

Circle the number which best describes how you feel. There are no right or wrong answers.

Do not spend too much time on any one statement, but give the answer which seems to describe how you generally feel.

1 Almost never
2 Sometimes
3 Often
4 Almost always

21.	I feel pleasant.	1	2	3	4

24.	I wish I could be as happy as others seem to be.	1	2	3	4
25.	I feel like a failure.	1	2	3	4
26.	I feel rested.	1	2	3	4
27.	I am "calm, cool, and collected".	1	2	3	4
28.	I feel that difficulties are piling up so that I cannot overcome them.	1	2	3	4
29.	I worry too much over something that really doesn't matter.	1	2	3	4
30.	I am happy.	1	2	3	4
31.	I have disturbing thoughts.	1	2	3	4
32.	I lack self-confidence.	1	2	3	4
33.	I feel secure.	1	2	3	4
34.	I make decisions easily.	1	2	3	4
35.	I feel inadequate.	1	2	3	4
36.	I am content.	1	2	3	4
37.	Some unimportant thought runs through my mind and bothers me.	1	2	3	4
38.	I take disappointments so keenly that I can't put them out of my mind.	1	2	3	4
39.	I am a steady person.	1	2	3	4
40.	I get in a state of tension or turmoil				

PART TWO

Read the following statements carefully. Then indicate how much you either agree or disagree by circling the number that represents your opinion.

1 I strongly disagree
2 I disagree
3 I am undecided
4 I agree
5 I strongly agree

Answer all the questions with only ONE answer.

If you make an error make sure you erase the undesired answer completely.
There are no right or wrong answers.

There is no time limit but do not spend too long on any one question.

1.	Jeers humiliate me even when I know I'm right.	1 2 3 4 5
2.	I worry about situations where I am being tested.	1 2 3 4 5
3.	The best way to teach a child right from wrong is to spank him when he is wrong.	1 2 3 4 5
4.	I must learn to "keep my head" when things go wrong.	1 2 3 4 5
5.	I think I am getting a fair deal in life.	1 2 3 4 5
6.	I worry about eternity.	1 2 3 4 5
7.	I am happiest when I am sitting around doing little or nothing.	1 2 3 4 5
8.	I prefer to be independent of others in making decisions.	1 2 3 4 5
9.	If a person is ill-tempered and moody, he will probably never change.	1 2 3 4 5

11.	Crime never pays.	1 2 3 4 5
12.	My family and close friends do not take enough time to become acquainted with my problems.	1 2 3 4 5
13.	People who do not achieve competency in at least one area are worthless.	1 2 3 4 5
14.	We are justified in refusing to forgive our enemies.	1 2 3 4 5
15.	I frequently feel unhappy with my appearance.	1 2 3 4 5
16.	I feel that life has a great deal more happiness than trouble.	1 2 3 4 5
17.	I worry over possible misfortunes.	1 2 3 4 5
18.	I often spend more time in trying to think of ways of getting out of something than it would take me to do it.	1 2 3 4 5
19.	I tend to look to others for the kind of behavior they approve as right or wrong.	1 2 3 4 5
20.	Some people are dull and unimaginative because of defective training as a child.	1 2 3 4 5
21.	Helping others is the very basis of life.	1 2 3 4 5
22.	School promotions should be for intellectual merit alone.	1 2 3 4 5
23.	It is very important to me when I do a good job to be praised.	1 2 3 4 5
24.	I find it difficult to take criticism without feeling hurt.	1 2 3 4 5
25.	It is terribly upsetting the way some	

26.	It is impossible at any given time to change one's emotions.	1 2 3 4 5
27.	I tend to worry about possible accidents and disasters.	1 2 3 4 5
28.	I need to learn how to keep from being too assertive or too bold.	1 2 3 4 5
29.	To cooperate with others is better than doing what you feel should be done.	1 2 3 4 5
30.	Sympathy is the most beautiful emotion of man.	1 2 3 4 5
31.	People who criticize the government are either ignorant or foolish.	1 2 3 4 5
32.	I wish that more affection were shown by members of my family.	1 2 3 4 5
33.	When a person is no longer interested in doing his best, he is done for.	1 2 3 4 5
34.	I get very angry when I miss a bus which passes only a few feet away from me.	1 2 3 4 5
35.	My place of employment and/or my neighborhood provide adequate opportunity for me to meet and make friends.	1 2 3 4 5
36.	I can walk past a grave yard alone at night without feeling uneasy.	1 2 3 4 5
37.	I avoid inviting others to my home because it is not as nice as theirs.	1 2 3 4 5
38.	I prefer to have someone with me when I receive bad news.	1 2 3 4 5
39.	It is necessary to be especially friendly to new co-workers and neighbors.	1 2 3 4 5
40.	The good person is usually right.	1 2 3 4 5

43.	Riches are a sure basis for happiness in the home	1 2 3 4 5
44.	I can face a difficult task without fear.	1 2 3 4 5
45.	I usually try to avoid doing chores which I dislike doing.	1 2 3 4 5
46.	I like to bear responsibilities alone.	1 2 3 4 5
47.	Other people's problems frequently cause me great concern.	1 2 3 4 5
48.	It is sinful to doubt the bible.	1 2 3 4 5
49.	It makes me very uncomfortable to be different.	1 2 3 4 5
50.	I get terribly upset and miserable when things are not the way I would like them to be.	1 2 3 4 5
51.	I find that my occupation and social life tends to make me unhappy.	1 2 3 4 5
52.	I am afraid in the dark.	1 2 3 4 5
53.	Many people that I know are so unkind or unfriendly that I avoid them.	1 2 3 4 5
54.	It is better to take risks and to commit possible errors, than to seek unnecessary aid of others.	1 2 3 4 5
55.	I get disturbed when neighbors are very harsh with their little children.	1 2 3 4 5
56.	I find it very upsetting when important people are indifferent to me.	1 2 3 4 5
57.	I have sometimes had a nickname which upset me.	1 2 3 4 5
58.	I have sometimes crossed the street to avoid meeting some person.	1 2 3 4 5

PART THREE

This section consists of a questionnaire to find out the way in which certain important events in our society affect people.

Each item consists of a pair of alternatives lettered (a) or (b).
Please select the one statement of each pair, which you more strongly BELIEVE to be the case as far as you are concerned.

It is important to select the one you actually BELIEVE to be more true rather than the one you think you should choose or the one you would like to be true.

There are no right or wrong answers.

1. (a) Children get into trouble because their parents punish them too much.

   (b) The trouble with most children nowadays is that their parents are too easy with them.

2. (a) Many of the unhappy things in people's lives are partly due to bad luck.

   (b) People's misfortunes result from the mistakes they make.

3. (a) One of the major reasons why we have wars is because people don't take enough interest in politics.

   (b) There will always be wars, no matter how hard people try to prevent them.

4. (a) In the long run people get the respect they deserve in this world.

   (b) Unfortunately, an individual's worth often passes unrecognized no matter how hard he tries.

5. (a) The idea that teachers are unfair to students is nonsense.

   (b) Most student's don't realize the extent to which their grades are influenced by accidental happenings.

6. (a) Without the right breaks one cannot be an effective leader.

   (b) Capable people who fail to become leaders have not taken advantage of their opportunities.

7. (a) No matter how hard you try some people just don't like you.

   (b) People who can't get others to like them don't understand how to get along with others.

8. (a) Heredity plays the major role in determining one's personality.

   (b) It is one's experiences in life which determine what they're like.

9. (a) I have often found that what is going to happen will happen.

   (b) Trusting to fate has never turned out as well for me as making a decision to take a definite course of action.

10. (a) In the case of the well prepared student there is rarely if ever such a thing as an unfair test.

    (b) Many times exam questions tend to be so unrelated to course work that studying is really useless.

11. (a) Becoming a success is a matter of hard work, luck has little or nothing to do with it.

    (b) Getting a good job depends mainly on being in the right place at the right time.

12. (a) The average citizen can have an influence in government decisions.

    (b) This world is run by the few people in power, and there is not much the little guy can do about it.

14. (a) There are certain people who are just no good.

(b) There is some good in everybody.

15. (a) In my case getting what I want has little or nothing to do with luck.

(b) Many times we might just as well decide what to do by flipping a coin.

16. (a) Who gets to be the boss often depends on who was lucky enough to be in the right place first.

(b) Getting people to do the right thing depends upon ability; luck has little or nothing to do with it.

17. (a) As far as world affairs are concerned, most of us are the victims of forces we can neither understand, nor control.

(b) By taking an active part in political and social affairs the people can control world events.

18. (a) Most people don't realize the extent to which their lives are controlled by accidental happenings.

(b) There is really no such thing as ''luck''.

19. (a) One should always be willing to admit mistakes.

(b) It is always best to cover up one's mistakes.

20. (a) It is hard to know whether or not a person really likes you.

(b) How many friends you have depends upon how nice a person you are.

21. (a) In the long run the bad things that happen to us are balanced by the good ones.

22. (a) With enough effort we can wipe out political corruption.

(b) It is difficult for people to have much control over the things politicians do in office.

23. (a) Sometimes I can't understand how teachers arrive at the grades they give.

(b) There is a direct connection between how hard I study and the grades I get.

24. (a) A good leader expects people to decide for themselves what they should do.

(b) A good leader makes it clear to everybody what their jobs are.

25. (a) Many times I feel that I have little influence over the things that happen to me.

(b) It is impossible for me to believe that chance or luck plays an important role in my life.

26. (a) People are lonely because they don't try to be friendly.

(b) There's not much use in trying too hard to please people, if they like you, they like you.

27. (a) There is too much emphasis on athletics in high school

(b) Team sports are an excellent way to build character.

28. (a) What happens to me is my own doing

(b) Sometimes I feel that I don't have enough control over the direction my life is taking.

29. (a) Most of the time I can't understand why politicians behave the way they do.

PART FOUR

This questionnare is designed to determine the way different people view certain important health-related issues.

Each item is a belief statement with which you may agree or disagree.

Each statement can be rated on a scale which ranges from strongly disagree (1) to strongly agree (6).

Please record the number that represents the extent to which you disagree or agree with the statement.

> The more strongly you agree with a statement, then the higher will be the number you record.
>
> The more strongly you disagree with a statement, then the lower the number will be that you record.

Please record only the number per item.

There are no right or wrong answers.

1 = Strongly disagree

2 = Moderately disagree

3 = Slightly disagree

4 = Slightly agree

5 = Moderately agree

6 = Strongly agree

SECTION A

____ 1. If I get sick, it is my own behavior which determines how soon I get well again.

____ 2. No matter what I do, if I'm going to get sick, I will get sick.

____ 4. Most things that affect my health happen to me by accident.

____ 5. Whenever I don't feel well, I should consult a medically trained professional.

____ 6. I am in control of my health.

____ 7. My family has a lot to do with my becoming sick or staying healthy.

____ 8. When I get sick, I am to blame.

____ 9. Luck plays a big part in determining how soon I will recover from an illness.

____ 10. Health professionals control my health.

____ 11. My good health is largely a matter of good fortune.

____ 12. The main thing which affects my health is what I myself do.

____ 13. If I take care of myself, I can avoid illness.

____ 14. When I recover from an illness, it's usually because other people (for example, doctors, nurses, family, friends) have been taking good care of me.

____ 15. No matter what I do, I'm likely to get sick.

____ 16. If it's meant to be, I will stay healthy.

____ 17. If I take the right actions, I can stay healthy.

SECTION B

1 = Strongly disagree

2 = Moderately disagree

3 = Slightly disagree

4 = Slightly agree

5 = Moderately agree

6 = Strongly agree

___ 1. If I become sick, I have the power to make myself well again.

___ 2. Often I feel that no matter what I do, if I am going to get sick, I will get sick.

___ 3. If I see an excellent doctor regularly, I am less likely to have health problems.

___ 4. It seems that my health is greatly influenced by accidental happenings.

___ 5. I can only maintain my health by consulting health professionals.

___ 6. I am directly responsible for my health.

___ 7. Other people play a big part in whether I stay healthy or become sick.

___ 8. Whatever goes wrong with my health is my own fault.

___ 9. When I am sick, I just have to let nature run its course.

____ 10. Health professionals keep me healthy.

____ 11. When I stay healthy, I'm just plain lucky.

____ 12. My physical well-being depends on how well I take care of myself.

____ 13. When I feel ill, I know it is because I have not been taking care of myself properly.

____ 14. The type of care I receive from other people is what is responsible for how well I recover from an illness.

____ 15. Even when I take care of myself, it's easy to get sick.

____ 16. When I become ill, it's a matter of fate.

____ 17. I can pretty much stay healthy by taking good care of myself.

____ 18. Following doctor's orders to the letter is the best way for me to stay healthy.

The following pages contain a list of statements that people use to describe themselves. They are printed here to help you describe your feelings and attitudes.

Try to be as honest and serious as you can in marking the statements as they apply to you. There are no right or wrong answers.

Do not be concerned that a few of the statements will seem unusual to you; they are included to describe people with many problems.

When you agree with a statement or decide that it describes you,
CIRCLE the T, to mark it TRUE.

If you disagree with the statement or decide that it does not describe you,
CIRCLE the F, to mark it FALSE.

Try to mark every statement even if you are not sure of your choice. If you have tried your best and still cannot decide, mark the F for FALSE.

1. T F I have always been able to overcome the problems I've had.
2. T F Lately, life has been going along as usual, with no special things happening.
3. T F When I was a young child, my parents felt very proud of me.
4. T F I have almost never been sick.
5. T F I have friends who will listen to any problems I have.
6. T F I like to be the one in authority to take charge of things.
7. T F If I were very sick, I'm sure that everything would work out well.
8. T F I always take the medicine a doctor tells me to even if I don't think it is working.
9. T F I am very pleased with all the things I have done up to now.
10. T F I almost never feel pressure in the work I do.
11. T F I get very frightened when I think of being all alone in the world.

12. T F I am ready to attack anyone who tries to say terrible things about me.
13. T F I have a feeling that things in my life just go from bad to worse.
14. T F All my life I have to "blow up" every now and then.
15. T F This year I was successful at something that was very important to me.
16. T F I am in better health than most of my friends.
17. T F A quiet hobby is more fun for me than a party.
18. T F Most people wouldn't care much if I were very sick.
19. T F I often say things that I regret having said.
20. T F I have lots of plans of what I'd like to be doing ten years from now.
21. T F I have a lot of faith that doctors can cure any sickness.
22. T F People can influence me quite easily.
23. T F I often find time to take it easy and do nothing.
24. T F Even in difficult times, I always try to be cheerful.
25. T F I don't mind that other people are not interested in my friendship.
26. T F I've had serious money problems this past year.
27. T F I almost always have medical problems.
28. T F I often feel that others do not want to be friendly to me.
29. T F If I became ill I wouldn't have much help from my family.
30. T F In many ways I feel superior to most people.
31. T F If I ever get a serious illness, I think it would be the end of me.
32. T F No matter what, seeing a doctor can make me feel better.
33. T F So little of what I have done has been appreciated by others.

34. T F Keeping to a time schedule is not important to me.

35. T F I've done most things in my life very well.

36. T F When I think about the past, I remember mostly the good things.

37. T F I make nasty remarks to people if they deserve it.

38. T F I have had more than my share of troubles in the past year.

39. T F It is good to have a regular way of doing things to avoid mistakes.

40. T F Many people have been spying into my private life for years.

41. T F I almost never worry about my health.

42. T F If I thought I had a serious sickness, I would quickly talk it over with my family.

43. T F There are always a number of reasons why most problems can't be solved.

44. T F I look forward to the future with lots of hope.

45. T F I do my best to get along with others by being pleasant and agreeable.

46. T F All doctors care about is my money, not me.

47. T F I get upset when things I don't expect happen to me.

48. T F I often get angry with people who do things slowly.

49. T F I don't depend much on other people for friendship.

50. T F I feel pretty upset about most things in my life.

51. T F It is very difficult for me to stop feelings from coming out.

52. T F My family has had really bad problems in the past year.

53. T F I can stand a lot of pain.

54. T F I like to flirt a lot.

55. T F In time of trouble there are several friends that I can depend on.

56. T F Most people can be trusted to be kind and thoughtful.

57. T F Even if I were very sick, I'd keep fighting and never give up.

58. T F I sometimes feel I am in this world all alone.

59. T F I feel that the doctors I have seen are not interested in my problems.

60. T F I am a dramatic and showy sort of person.

61. T F I can't stand people who are late for appointments.

62. T F I do my best to stop anyone from trying to boss me.

63. T F I often think about unhappy things that have happened to me.

64. T F I often do things for no reason other than it might be fun.

65. T F During the past year, someone close to me has been very ill.

66. T F I guess I am a complainer who expects the worst to happen.

67. T F It is not unusual to feel lonely and unwanted.

68. T F I worry a lot about my health.

69. T F Lots of people would care about me if I became very sick.

70. T F I would much rather follow someone than be the leader.

71. T F If I had a very serious sickness, I think I would fall apart mentally.

72. T F To get ahead in this world I am willing to push people who get in my way.

73. T F Doctors have always been helpful to me.

74. T F I find it hard to feel sorry for people who are always worried about things.

75. T F I seem to fit in right away with any group of people I meet.

76. T F I like being in a crowd just to be with lots of people.

77. T F Most of my problems just go on and on.

78. T F I guess I depend too much on others to be helpful to me.

79. T F I moved during the past year.

80. T F I have always felt some kind of problem between me and the opposite sex.

81. T F I get frightened when I think I have a medical problem.

82. T F Punishment never stopped me from doing whatever I wanted.

83. T F I would have lots of visitors if I were in the hospital.

84. T F Among the most important things a person can have are a strong will and the drive to get ahead.

85. T F I would never let a serious sickness stop me from working toward the future.

86. T F I often feel so angry that I want to throw and break things.

87. T F I dislike going to doctors, and do so only after trying everything myself.

88. T F I really hate to have my work pile up.

89. T F I find it hard to take my mind off my work even when I'm supposed to be relaxing.

90. T F I have not seen a car in the last ten years.

91. T F I very often think I am not wanted by others in a group.

92. T F Even when things seem to be going well, I expect that they'll soon get worse.

93. T F I would rather be direct with people than avoid telling them something they don't like.

94. T F Many important things have happened in my life this past year.

95. T F What this country really needs are more serious and devoted citizens.

96. T F At no time in my life have I had any hair on my head or my body.

97. T F T.V. programs about illness make me very upset.

98. T F Ever since I was a child I have been losing touch with the real world.

99. T F I cannot depend on my family when I need them.

100. T F I like to tell others about the things I have done well.

101. T F I'd rather be dead than have a very serious sickness.

102. T F I usually let other people have their own way.

103. T F I usually won't take any medicines, even if the doctor tells me to.

104. T F I wish the people around me would move faster and get more things done.

105. T F I often feel that there is nothing I can do to make my life easier.

106. T F I have very few close personal ties with others.

107. T F This past year has been one of the most difficult ones in my life.

108. T F If I thought I were getting sick, I would quickly call a doctor.

109. T F I have a strong desire to win any game I play with others.

110. T F Nobody really cares about my state of health.

111. T F I have faith that human nature is good.

112. T F I haven't thought much about what I'll be doing a year from now.

113. T F All my life I have had the feeling that I have done something terribly wrong or evil.

114. T F When someone hurts me, I try to forget it.

115. T F Hospitals are frightening and lonely places to be in.

116. T F My work makes me tense almost all the time.

117. T F I have flown across the Atlantic 30 times last year.

118. T F In this world you either push or get shoved.

119. T F If I were young again, I would do things very differently.

120. T F It is very important that children learn to obey their elders.

121. T F I have had a lot of shocks and disappointments this past year.

122. T F Rather than demand things, people can get what they want by being gentle and thoughtful.

123. T F I get very upset when I feel pain in any part of my body.

124. T F I can see more sides of a problem better than others can.

125. T F If I were getting sick, I wouldn't waste my time telling anyone in my family.

126. T F I am more worried about finishing things that I start than most people.

127. T F For me, the future looks like it will be full of trouble and problems.

128. T F I do my best not to hurt people's feelings.

129. T F I have never felt much life in me.

130. T F I would rather be in pain than take any medicines.

131. T F I often doubt whether people are really interested in what I am saying to them.

132. T F It is very easy for me to relax and slow down.

133. T F I don't know what I want out of life.

134. T F Life has never gone well for me.

135. T F I've been touchy or tearful about everything most of my life.

136. T F I am very uneasy when I have to tell people what to do.

137. T F I am too rushed and busy to take the vacations I should.

138. T F There has recently been an important change in my job.

139. T F I like to follow instructions and do what others expect of me.

140. T F I often think that I have a serious illness.

141. T F I am a quiet and cooperative person.

142. T F I'd be a pretty lonely person if I were ever hospitalized.

143. T F I become very excited or upset once a week or more.

144. T F I always try to do what is proper.

145. T F I don't think I would want to go on living if my body was marked up a lot in a serious operation.

146. T F I get so touchy that I can't talk about certain things.

147. T F From things I hear about them, I don't trust the people who work in hospitals.

148. T F I have a strong need to feel like an important person.

149. T F My day is filled with pressures and responsibilities.

150. T F I like to arrange things down to the last detail.

Demographic Data

Sex: Male / Female

Marital Status: ----------

Age: ----------

Education Attained: Elementary / High School / University

Highest Degree Obtained: ----------

Please check ( ) if you have any of the following chronic health problems:

Arthritis ----------

Asthma ----------

Chronic or recurring Bladder or Kidney conditions --------

Cancer ---------

High Blood Pressure ----------

Cirrhosis ----------

Diabetes ---------

Eczema ---------

Emphysema ---------

Migraine Headaches ----------

Multiple Sclerosis ----------

Ulcers ----------

Colitis ----------

Ileitis -------

Temporal Mandibular Jaw Syndrome (Clenching Jaw) ----------

Arteriosclerosis ----------

Heart Disease ----------

Lupus ----------

Other chronic illnesses not included in this listing --------

---

Thank you very much for your time and participation in this research. I appreciate your input.

Marilyn Hundleby
Ph.D Candidate
University of Alberta

Dr. H.W. Zingle
Associate Dean of Education
Professor
Educational Psychology
University of Alberta

APPENDIX B

INTERSTITIAL CYSTITIS ASSOCIATION QUESTIONNAIRE

GENERAL INFORMATION

Date: _____

Date of Birth: -----/---/----
month/day/year
Place of Birth: city/country ----------/----------

Sex: M / F

Race / Ethnic Heritage:

Parent's Place of Birth: Mother:
Father:

Height: _____ Weight: _____

Marital Status: _____

Educational Attainment: Elementary / High School / University
Highest Degree Obtained: _____

FAMILY MEDICAL HISTORY

Please answer yes or no to the following: is there any history in your family (i.e. others than yourself) of the following problems?

	Yes	No
Urological Problems:		
Interstitial Cystitis		
Kidney Problems		
If Yes, please specify:		
Cystitis / urinary tract infections		
Prostate Problems		
Others:		
Diabetes		
Ulcers		
Allergies		
If Yes, please specify:		

	Yes	No
Circulatory problems - high blood pressure		
heart disease		
Arthritis		
Cancer		
Ulcerative colitis		
Mental illness		
Migraines		
Multiple Sclerosis		
Gout		
Other		

CHILDHOOD

Order of Birth: were you first / middle / last - born?

Type of Birth: natural / caesarean

Did you suffer from any birth defects? _____
If so, please specify: _____

As a child, did you suffer from any of the following?

	Yes	No
Urological Problems:		
Infections		
Bedwetting		
Frequency		
Pain		
Surgery anywhere in the system (e.g. bladder, kidney)		
Unusual toilet training		
Please explain:		
Other Medical Problems:		
Allergies to Food		
If Yes, please specify:		
to Drugs		
If Yes, please specify:		
to Inhalants (smoke, pollen etc.)		
If Yes, please specify:		
to Material		
If Yes, please specify:		
to Metals		
If Yes, please specify:		
to Other (please specify:		
Childhood Diseases:		
Chicken Pox		
Measles		
Mumps		

	Yes	No
Serious Diseases:		
Rheumatic fever		
Heart disease		
Juvenile diabetes		
Acute tonsillitis		
Asthma		
Hepatitis		
Anemia		
Sinusitis		
Other (please specify)		
Back trouble		
If Yes, please specify:		
Sleep trouble		
If Yes, please specify:		
Unusual sleep habits		
If Yes, please specify:		
Frequent viral infections (e.g. colds, flu)		
Surgery		
If Yes, please specify:		
As a child, were you ever in a minor accident?		
a major accident?		
Did you ever have fainting spells?		
Did your joints swell easily?		
Lifestyle:		
As a child, did you consume a lot of the following?		
Sugar		
Acidic foods		
Coca-cola		
Milk		
Spicy foods		
Salty foods		
Family and environment:		
Did you suffer from sexual abuse?		
emotional abuse?		
family breakup?		
traumatic experience (please explain)		
Did anyone in your family smoke?		
Were you ever told to hold your urine, or did you ever try even while you had to go?		

If there is anything in your childhood not covered by these questions, but which you feel might be relevant, please explain, being as specific as possible:

ADOLESCENCE

	Yes	No
Was the onset of puberty normally timed?		
Would you say that you adjusted well to puberty?		
What was the approach to sex in your household?		
Open		
Somewhat open		
Somewhat repressed		
very repressed		
How did you learn about sex?		
Family		
Friends		
School		
Other		
Were you sexually active?		
Did you masturbate?		
Did you take drugs?		
Legal		
Illegal		
Did you smoke?		
Were you athletic?		
As an adolescent, did you suffer from any of the following?		
Bladder problems		
Bladder infections		
Gynecological infections		
Acne		
Hormonal problems		
Migraines		
Unusual menstruation		
Unusual ovulation		
Serious diseases		
Please specify (use the list on page 2 as a guide):		
Other		
Please specify:		

	Yes	No
ADULTHOOD		
Age of marriage (if applicable): _____		
Have you been diagnosed as having Interstitial Cystitis?		
If not, how have you been diagnosed? Please specify: _____		
Prior to the onset of I.C. (or related condition), did you suffer from any of the following?		
Attacks of bacterial cystitis - occasional		
- recurrent		
Other urinary tract infections - occasional		
- recurrent		
Yeast infections - occasional		
- recurrent		
Pelvic Inflammatory Disease		
V.D. (please specify):		
Liver/ kidney problems: jaundice		
hepatitis		
diabetes		
Circulatory problems: anemia		
high blood pressure		
heart disease		
Back trouble (please specify):		
Sexual dysfunction		
Periodontal problems		
Bowel trouble: constipation		
diarrhea		
Ulcerative colitis		
Arthritis		
Appendicitis		
Viral infections: herpes		
colds, flu, etc.		
Asthma		
Cancer		
Dry lips		

Would you say that you are physically overly sensitive (e.g. to temperature, pain)?

	Yes	No
Do you have any intolerances to the following?		
Spice		
Foods: milk products		
acidic foods		
sugar		
other (please specify):		
Did you ever undergo surgery? - appendix		
- gastrointestinal		
Were you allergic to any of the following?		
Inhalants		
Drugs		
Other (please specify):		
At the time of onset of I.C., were you experiencing any of the following?		
Bladder infection		
Coldness		
Fatigue		
Serious disease (please specify):		
Unusual diet / strange foods		
Stress		
Trauma		
Unusual sexual activity		
Self-absorbed:		
were you especially aware of your physical condition?		
were you especially aware of your bladder condition?		

Anything else that was unusual? (please specify):

DIAGNOSIS AND TREATMENT OF I.C.

How long a time passed before you sought a diagnosis? _____

before you received a diagnosis? (even a wrong one) _____

If you were at first not diagnosed as having I.C., what were you told you had? _____

How were you treated for it? _____

How long did you undergo this treatment? _____

Did this treatment help? _____

How much time passed between the onset of your symptoms and the diagnosis of Interstitial Cystitis? _____

What diagnostic techniques were employed?			
	Cystoscopy		
	Biopsy		
	Urodynamics		

For the following, please indicate which treatments you have tried by saying whether the treatment was successful, partially successful, or unsuccessful in relieving your symptoms:

	Successful	Partially Successful	Unsuccessful
DMSO (Rimso 50)			
Anticholinergics:			
Bentalol			
Probanthine			
Ditropan			
Inipramine			
Analgesics:			
Pyridium			
Aspirin			
Dilatation			
Cauterization			
Cortisone			
Prednisone			
Saline			
Chlorpactin			
Elmiron			
Valium			
Bladder Augmentation			
Antihistamines			
Other:			

SYMPTOMS

	Yes	No
Do your symptoms come and go?		
Which of the following symptoms do you have?		
Frequency:		
How often do you have to go?		
Pain: Bladder		
Abdomen		
Burning Urination		
Urethra		
Lower back / flank		
Nocturia:		
How often do you have to get up at night?		
Urgency		
Hesitancy-you need to go but can't start		
Weak stream		
Dribbling		
Incontinence		
Inability to empty bladder		
Depression		

When are your symptoms present?

	Before Urination	During	After Urination
Pain			
Urgency			

	Yes	No
Does your I.C. affect your sexual functioning?		

Have you experienced problems in your ability to conceive? _____
bear children? _____
bring pregnancy to full term? _____

We would like to find out WHAT AFFECTS YOUR SYMPTOMS, FOR BETTER OR WORSE.
Please indicate whether any of the following affects your symptoms; if something has no effect, leave the spaces blank. Feel free to add anything you find relevant to yourself.

	Pain		Urgency		Frequency	
	Better	Worse	Better	Worse	Better	Worse
Diet:						
Spicy foods						
Acidic foods						
Yeasty foods						
Alcohol						
Sweets						
Amount of liquid consumed						
large:						
small:						
Wine						
Tea/coffee/cola						
Others (specify):						
Nervousness						
Fatigue/sleepiness						
Sexual activity						
Menstruation:						
before:						
after:						
Coldness						
Heat						
Bowel movement						
before:						
during:						
after:						
Constipation						
Smoking						
Having a cold, flu, etc.						
Being pregnant						
Travel						
Any difference in type of vehicle e.g.						
plane:						
train:						
car:						
Exercise or physical exertion						
Physical position						
standing:						
sitting:						
lying down:						
Time of day						
morning:						
afternoon:						
evening:						
night:						

	Pain		Urgency		Frequency	
	Better	Worse	Better	Worse	Better	Worse
Time of month						
near period:						
far from period:						

	Yes	No
After urinating, do you feel spasms in your bladder?		
urinary tract?		

If you do not go right away, can you explain how you feel?

IS THERE ANYTHING ELSE you would like to add? If so, please use the blank space below for your additional information.
Thank you for your co-operation.

Interstitial Cystitis Study

Marital Status: married ____
single ____
divorced ____
widow/widower ____

Have you had a child/children ? yes ____
no ____

Age you were at onset of Interstitial Cystitis ________

What year was your Interstitial Cystitis diagnosed? ________

Do you have any allergies, and if so please specify _____

_____

_____

Is there any history of bladder problems in your family of origin, and if so please specify?

_____

_____

_____

_____

Do you take medication for Interstitial Cystitis, and if so what?

_____

_____

Have you had any pelvic surgery _____

_____

How often do you experience painful symptoms associated with Interstitial Cystitis:

almost continually ------

1 or 2 times per month -----

once every several months -----

2 times per year ------

other, please specify ----------

When experiencing the symptoms of Interstitial Cystitis, how often do you experience FREQUENCY:

50 - 60 times per day -----

40 - 50 times per day -----

30 - 40 times per day -----

20 - 30 times per day -----

10 - 20 times per day -----

less than 10 times -----

Would you describe your pain as:

constant burning -----

a dull ache -----

annoying -----

debilitating -----

at times, unbearable ------

other.. please describe ----------

I sincerely appreciate your help in this research. Your participation as a Co-researcher in sharing your insights, along with the candor with which you have answered the questions, will help us better understand this very important health problem.

My heartfelt Thanks!

Marilyn Hundleby

APPENDIX C

LETTER TO UROLOGISTS IN ALBERTA

University of Alberta
Edmonton
Canada T6G 2G5

Faculty of Education
Office of the Dean
845 Education Building South, Telephone (403) 432-3751

March 20, 1989

Dear Colleague,

Within the next two months, a research study will commence to examine psychosocial correlates in patients diagnosed with Interstitial Cystitis. The project requires the assistance of urologists in referring two distinct groups of patients. Firstly, we require a group of cystoscopically diagnosed cases of Interstitial Cystitis. Uniformity of diagnosis is crucial to ensuring sample homogeneity.

The second group of subjects for comparison, will be comprised of chronic cystitis patients. We ask that in referring patients to this study the diagnosis of either Interstitial Cystitis or Cystitis be indicated.

The design of this project requires a relatively large sample, and for this reason we would greatly appreciate your assistance and support in researching this particularly difficult urological condition. The National Institutes of Health in Bethesda, Maryland, has recently called for requests for grants to research Interstitial Cystitis, following some extensive lobbying of government in the United States.

We would ask that you forward the names and phone numbers of consenting individuals willing to participate in this doctoral research. Following your referrals, patients will be contacted by the researcher, Marilyn Hundleby, a Ph.D candidate at the University of Alberta. At that time she will schedule participants for data collection, and in some cases possibly an in-depth interview.

We hope to begin contacting referred patients in April. Data collection will, in all likelihood continue into the summer.

We appreciate your time in a busy schedule. Marilyn will contact your office to answer any questions you may have upon receipt of this letter. Referrals may be directed to her at 433-2110 or 439-7447, or by mail to:

Marilyn Hundleby
Suite 1603, 9929 Saskatchewan Drive
Edmonton, Alberta
T6E 5J9

We are excited about this research and look forward to hearing from you.

Sincerely,

W. H. Lakey, M.D., F.R.C.P.(C)
Professor
Surgery
Walter C. MacKenzie Health Sciences Center
University of Alberta

H. W. Zingle, Ph.D.
Associate Dean of Education
Professor, Educational Psychology
University of Alberta

Marilyn Hundleby, M.Ed.
Ph.D. Candidate
University of Alberta

APPENDIX D

LETTER TO RANDOM SAMPLE

University of Alberta
Edmonton
Canada T6G 2G5

Faculty of Education
Office of the Dean
845 Education Building South, Telephone (403) 492-3751

September 28, 1989

Dear

We are conducting an important research study, seeking insight into why people get sick. Using a random sample from the general population, we are now approaching the final phase of this research. Your participation is essential to the analysis of extensive data collected across Alberta and in Ontario.

Research studies within the medical field are only now beginning to investigate life stresses and how they may pertain to the overall health of an individual. Your contribution to this project will be invaluable in helping to expand the scope of a more holistic medical knowledge.

We appreciate that you receive unsolicited requests or phone calls to participate in telephone surveys from time to time. For this reason, we are sending a preliminary letter, prior to contacting you by phone. At that time, if you have any questions about the study, we will be happy to discuss them with you.

We look forward to talking with you, and will call your home within the next week.

Sincerely,

Harvey W. Zingle Ph.D
Associate Dean of Education
Professor, Educational Psychology
University of Alberta

Marilyn Hundleby
Ph.D Candidate
University of Alberta

APPENDIX E

STRUCTURED INTERVIEW SCHEDULE

Interview Schedule

Draw a picture of yourself and your disease.

Draw a picture of your disease

Tell me about your drawings.

What words would you use to describe your illness?

Describe what interstitial cystitis is like for you?

In what ways has interstitial cystitis affected your life?

When your condition is at its worst, how would you describe it

Complete the following:

Sometimes my interstitial cystitis has been so bad, I have felt like . . . . .

Where are the places in your body, that you are aware of holding tension?

What was it like for you growing up?

Do you recall any event in your life which may have contributed to, or precipitated the onset of interstitial cystitis?

What happened the year or two before you became ill?

If you could somehow turn your ear inward and listen to the messages that your body is giving you when you are ill, what would they be?

What are the benefits of your illness?

Are there any ways you can think of, that you are hard on yourself in terms of your expectations, or the expectations of others?

What were some of the "messages" you got from your parents as you were growing up?

What did you discover, if anything about your marriage, because of your illness?

Are there any ways in which interstitial cystitis has affected your sexual relationship and would you feel comfortable talking about this?

What are some of the ways in which you release daily tension?

As you were growing up, what did you think and feel about expressing your feelings or emotions?

- how was this generally done within your family?

What do you do with your feelings now, as an adult?

Is there any particular emotion that you feel frequently? Would you feel comfortable talking about it at this time?

In what ways are you 'good' to yourself?

In what way has interstitial cystitis affected or altered your outlook on life?

What do you think you need to be essentially healthy?

What are some of your most pertinent concerns, worries or fears in life?

Are there any areas in your life where you perceive yourself to be a perfectionist? If so, would you explain.

Do you practice any form of relaxation, meditation or visualization on a regular basis?

What are some of your greatest fears or insecurities ?

What do you do with your anger?

How does illness play a role in your friendship with people?

If you could summarize the most important thing that you have learned from being ill, what would you say?